

IAS

ways. With
and childrean
er a couple
n the gesta-
such dilem-
sponsibility

MAN

aging tech-
ties or fetal
her, such as
y, and fetal
fetal disor-
m, provided
of the fetus
and pregnant

with a seri-
sponsibility
sicians have
themselves.
will be born;

to the fetus
affect other
he pregnant
m caring for
accept side
born. How-
egardless of
ll become a
living chil-
to children

ing consent.

ION

is (5). They
perform an
ections, and

ion, sexually
in such care
sponsibility.

In most states, however, adolescents may seek reproductive health care without parental consent. The rationale is that it is preferable for adolescents to have access to such care rather than to forego care because they are reluctant or unable to obtain parental approval. Usually it is in the adolescent's best interest to involve parents in their care, and physicians should encourage them to do so. However, in some cases adolescents might have compelling reasons for not involving parents—for example, in cases of domestic violence or incest. Chapter 37 discussed ethical issues in adolescent medicine in detail.

ROUTINE PRENATAL TESTING

During pregnancy women commonly have screening tests for rubella, syphilis, gonorrhea, Rh type, and diabetes. The Centers for Disease Control and Prevention (CDC) now recommend routine prenatal human immunodeficiency virus testing (6). In many ambulatory tests the patient usually assents rather than gives full informed consent. Each test's risks, benefits, and alternatives are not discussed, and testing is carried out unless the patient objects. Another way to describe routine testing is that women may opt out of testing but do not need to give affirmative consent. Going beyond routine testing, most states require mandatory prenatal testing for syphilis (7). The ethical justification for routine and mandatory prenatal screening tests are prevention of harm to children who will be born, the failure of voluntary testing to achieve the desired level of testing, and the belief that the infringement of the woman's autonomy is acceptable.

OBSTETRIC EMERGENCIES

Some obstetric decisions need to be made in crisis situations. An uncomplicated pregnancy at term might unexpectedly and rapidly become an emergency if severe fetal distress develops or if the umbilical cord is wrapped around the fetus's neck. A cesarean section might need to be carried out within minutes in order to prevent severe, irreversible harm to a child. As with any emergency situation, the informed consent process may be truncated if delaying care to obtain consent would cause serious harm and if most patients would agree to the intervention if fully informed. In an emergency a cesarean section may be performed on the basis of the pregnant woman's assent rather than informed consent. That is, the patient agrees to the doctor's recommendations without being informed of all the procedure's risks and benefits. Almost all pregnant women agree to recommended emergency cesarean sections (8).

STERILIZATION

Sterilization without a woman's consent is a grave violation of her autonomy. In the early 1900s nonvoluntary eugenic sterilization was carried out in the United States on women who had mental retardation, resided in psychiatric institutions, and were prisoners (9,10). African-American women were disproportionately subjected to nonvoluntary sterilization. In response to these abuses, many states have enacted procedural requirements such as waiting periods to ensure that sterilization decisions are voluntary and informed (9,10).

Sterilization is commonly considered for severely mentally disabled persons. It might be in the best interests of a person who will never have the capacity to make informed reproductive decisions or to provide basic care for a child (11). Generally, a court hearing is required in order to sterilize a woman who is not capable of giving informed consent (9,10).

ELECTIVE CESAREAN SECTION AT TERM

Traditionally, obstetricians have opposed pregnant women's requests for elective cesarean section deliveries at term. Most obstetricians believed that this procedure presented unacceptable risks to the mother and child. In addition, many believed that convenience and the mother's preferences were not adequate reasons for a surgical procedure. Recently, attitudes have shifted dramatically (12). New evidence suggests that elective cesarean sections at term might benefit the mother and fetus (12). Operative and anesthetic advances have decreased risks to the mother. Many obstetricians report that they would choose this procedure for themselves or their partner (13).

ABORTION

Debates over abortion in the United States are contentious. Pro-life advocates contend that the fetus is a person with a right to live and that abortion constitutes a form of murder. Pro-choice advocates claim that women have a right to control their bodies and their reproductive choices and often contend that a fetus becomes a person only after birth. Disagreements over abortion are associated with different views on women's roles and the meaning of their lives (14). Although pro-life activists tend to view motherhood as the "most important and satisfying role" for a woman, pro-choice activists tend to believe that motherhood is "only one of several roles, a burden when defined as the only role" for a woman (15). Debates have become increasingly polarized (1,14).

The Supreme Court has made several important rulings on abortion. In *Planned Parenthood v. Casey* (1992) the Supreme Court affirmed the landmark 1973 *Roe v. Wade* decision, which protected a woman's right to choose to abort her fetus. In *Casey* the court held that states may ban abortion after fetal viability, as long as exceptions were made to protect the woman's health or life and as long as the restriction's "purpose or effect [was not] to place substantial obstacles in the path of a woman seeking an abortion before the fetus attains viability (16)." Many states require parental notification if a minor seeks an abortion; these states must have a procedure for adolescents to seek judicial authorization for the procedure instead of parental notification. Physicians need to understand the laws in their state.

Some requests for abortion are particularly problematic. For example, a pregnant woman might seek an abortion on the basis of the sex of her fetus even though there is no sex-linked genetic disease. The woman might come from a culture in which male children are more prized or might desire a son or daughter after having all children of the opposite sex. Although parents commonly have a preference about the child's sex, a physician is not morally justified to perform an abortion on a healthy fetus solely because of its sex (17). There is little ethical justification for treating females and males differently in this situation. If the physician cannot persuade the woman to withdraw her request, the doctor is justified in withdrawing from the case.

MATERNAL-FETAL CONFLICT

Most pregnant women agree with their physician's recommendations for interventions that benefit the fetus. However, in some cases women might reject such recommendations despite continued attempts at persuasion.

PATIENT REQUESTS FOR INTERVENTIONS WHOSE RISKS OUTWEIGH THE BENEFITS

Pregnant women might request interventions whose balance of benefits to risks physicians consider unfavorable. For example, young pregnant women at low risk for genetic abnormalities might request amniocentesis or chorionic villus sampling. Such women might place a high value on information about the fetus and reassurance that the pregnancy is progressing normally, even though there is little likelihood of a serious abnormality (18). Moreover, women might want to know of congenital abnormalities even if they would still carry the fetus to term. However, if the risk for serious congenital abnormalities is very low, it might be less than the risk of complications such as miscarriage.

How should the physician respond to such requests? The physician can check that the mother understands the procedure's benefits and risks and the availability of other tests for congenital abnormalities, such as alpha fetoprotein screening. In addition, the physician can help the woman deliberate about the decision and make a recommendation. Ultimately, however, the woman's choice should be decisive.

CARE OF PREGNANT WOMEN WITH OTHER MEDICAL PROBLEMS

When pregnant women have serious medical problems, such as cancer, depression, or seizures, physicians are understandably concerned that treatments for those conditions might adversely affect the fetus. However, such concern for the fetus must not lead physicians to withhold effective therapies from the woman. First, physicians need accurate information about therapies' effects on

the fet
epilep
who v
health
ical pr
overall
mothe

SUBS

Many
2003,
drugs (
ing on
state n
testing
Except
ment o
and ak
prenata
likely t

FORC

If a pr
is requ
ings he
welfare
cesarea
often o
deliver
misc w
women

ASSIS

Beaus
the wel
infertili
chiatric
might l
married
Con
women
ring. T
needs, i
who are
ever, ph
views c
predict
many p
Som
ted to i
some w
having
who is

ontend that the
der. Pro-choice
ive choices and
ortion are asso-
lthough pro-life
a woman, pro-
a burden when
olarized (1,14).
d Parenthood v.
ion, which pro-
states may ban
a's health or life
obstacles in the
y states require
dure for adoles-
tion. Physicians

nt woman might
iked genetic dis-
prized or might
rents commonly
orm an abortion
tion for treating
e the woman to

tions that benefit
espite continued

THE BENEFITS

physicians con-
ormalities might
a high value on
s normally, even
n might want to
. However, if the
of complications

k that the mother
ts for congenital
help the woman
er, the woman's

sion, or seizures,
might adversely
withhold effective
rapies' effects on

the fetus, and physicians often overestimate the risks. Second, in conditions such as tuberculosis or epilepsy, aggressive treatment for the pregnant woman promotes the physical health of the child who will be born (19). Furthermore, it will be in the child's best interests for the mother to be healthy. Finally, the pregnant woman should make informed decisions about the care of her medical problems. She should decide what risks to the fetus are acceptable in view of the intervention's overall benefits. It is inappropriate for physicians to withhold effective interventions from the mother or to insist that the pregnant woman obtain an abortion as a condition of treatment.

SUBSTANCE AND ALCOHOL ABUSE DURING PREGNANCY

Many states have enacted laws to try to prevent harm caused by prenatal substance abuse. As of 2003, 24 states permit involuntary civil commitment of pregnant women who use certain illegal drugs (20). In a few states drug abuse during pregnancy triggers child abuse laws (20,21). Depending on the state, there may be an evaluation of parenting ability or a presumption of neglect. No state mandates drug screening during pregnancy. Physicians and hospitals may not conduct drug testing of pregnant women for criminal prosecution without a warrant or an explicit consent (21). Except in South Carolina, courts have refused to apply existing criminal laws on child endangerment or delivery of drugs to a minor to drug-using pregnant women. Punitive approaches to drug and alcohol abuse during pregnancy might be counterproductive, deterring women from seeking prenatal care or being candid with physicians (20,22). Focusing on substance abuse treatment is more likely to benefit the fetus's and the mother's health than punishment is (23,24).

FORCED CESAREAN SECTION DELIVERIES

If a pregnant woman cannot be persuaded to accept a cesarean section that the physician believes is required, some doctors seek court authorization for the operation. The trend in recent court rulings holds that a competent pregnant woman may refuse a cesarean section even if a viable fetus's welfare is at stake (22,25-27). Courts note that competent adults may refuse treatment, that cesarean sections are a significant bodily invasion, and that the medical need for the procedure is often overstated. In many cases in which court orders were sought for cesarean section, the woman delivered vaginally without complications (22,28). In addition, forced cesarean sections compromise women's trust in physicians and discriminate against women who do not speak English and women of color.

ASSISTED REPRODUCTIVE TECHNOLOGIES

Because physicians take an active and essential role in ARTs, they feel a moral responsibility for the well-being of the child who might be born (29). Many physicians would hesitate to provide infertility treatments to women with drug addiction, serious developmental delay, or severe psychiatric illness because they believe the woman would not be a good parent. Other physicians might be reluctant to assist single, unmarried, or lesbian women because they believe that only married women should be parents.

Concern for the well-being of children who will be born is laudable. Physicians should help women and couples who seek ARTs appreciate the difficulties of infertility treatments and childbearing. The physician might also make recommendations on the basis of the patient's situation, needs, and goals. Furthermore, it would be irresponsible for physicians to provide ARTs to women who are incapable of giving informed consent or to women who have abused their children. However, physicians should distinguish concerns that are based on clinical evidence from their personal views of parenthood and family. Some characteristics, such as marital status, have little power to predict whether a person would be a good parent (29). Many married couples fail as parents, but many persons who are single or have nontraditional relationships succeed.

Some women over 40 seek infertility treatment (29). Although many such women are committed to raising a child, have strong social support, and have carefully considered their decision, some writers believe that the natural span of childbearing years should be respected (30). Because having a child is such a private decision, it is problematic for third parties to impose their views of who is worthy of being a parent.

STUDENT PARTICIPATION IN GYNECOLOGIC AND OBSTETRIC CARE

Pelvic examinations done under anesthesia offer opportunities for students to master a difficult skill. Because a woman's muscles are relaxed under anesthesia, a more thorough examination is possible. Senior physicians sometimes ask students to perform pelvic examinations on an anesthetized patient in the operating room without her consent. Some persons believe that explicit consent is not needed because, by agreeing to the surgery, the patient implicitly consents to examinations by medical students. However, agreeing to surgery is not tantamount to consenting to a pelvic exam by an unknown medical student who is not providing ongoing care. In one study all the women surveyed believed that students should ask specific permission to perform a pelvic examination on an anesthetized patient (31). Although patient consent to participation by trainees in their care is always important (see Chapter 38), it is particularly important for pelvic examinations because of patient privacy. Under a recent California law, trainees may not perform a pelvic examination on an anesthetized or unconscious patient without informed consent unless the examination is within the scope of care for the patient (32).

In summary, obstetrics and gynecology raise ethical issues that might be particularly controversial. Physicians need to help women understand various options' risks and benefits. Doctors also need to appreciate that the patient's values might differ from their own, try to understand how the woman's decision might make sense from her perspective, and negotiate a mutually acceptable plan for care.

REFERENCES

1. McCullough LB, Chervenak FA. *Ethics in obstetrics and gynecology*. New York: Oxford University Press, 1994.
2. Dickens BM, Cook RJ. Ethical and legal approaches to "the fetal patient". *Int J Gynecol Obstet* 2003;83:85-91.
3. Steinbock B. Maternal-fetal relationship: ethical issues. In: Reich, WT, ed. *Encyclopedia of bioethics*, Revised ed. New York: Simon & Schuster Macmillan, 1995:1408-1413.
4. Murray TH. *The worth of a child*. Berkeley, Los Angeles, London: University of California Press, 1996:96-114.
5. Cantor J, Baum K. The limits of conscientious objection—may pharmacists refuse to fill prescriptions for emergency contraception? *N Engl J Med* 2004;351:2008-2012.
6. Wolf LE, Lo B, Gostin LO. Legal barriers to implementing recommendations for universal, routine prenatal HIV testing. *J Law Med Ethics* 2004;32:137-147.
7. Acuff KI. Prenatal and newborn screening: state legislative approaches and current practice standards. In: Faden RR, Geller G, Powers M, eds. *AIDS, women and the next generation*. New York: Oxford University Press, 1991: 121-165.
8. Lescale KB, Inglis SR, Eddleman KA, et al. Conflicts between physicians and patients in non-elective cesarean delivery: incidence and adequacy of informed consent. *Am J Perinat* 1996;13:171-176.
9. Dubler NN, White A. Fertility control: legal and regulatory issues. In: Reich WT, ed. *Encyclopedia of bioethics*, Revised ed. New York: Simon & Schuster Macmillan, 1995:839-847.
10. American Academy of Pediatrics Committee on Bioethics. Sterilization of minors with developmental disabilities. *Pediatrics* 1999;104:337-340.
11. Diekema DS. Involuntary sterilization of persons with mental retardation: an ethical analysis. *Ment Retard Dev Disabil Res Rev* 2003;9:21-26.
12. Minkoff H, Chervenak FA. Elective primary cesarean delivery. *N Engl J Med* 2003;348:298-302.
13. Al-Mufti R, McCarthy A, Fisk NM. Survey of obstetricians' personal preference and discretionary practice. *Eur J Obstet Gynecol Reprod Biol* 1997;73(1):1-4.
14. Murray TH. *The worth of a child*. Berkeley, Los Angeles, London: University of California Press, 1996:142-166.
15. Luker K. *Abortion and the politics of motherhood*. Berkeley: University of California Press, 1984.
16. Planned Parenthood of Southeastern Pennsylvania v. Casey. 112 US 674 (1992).
17. The New York State Task Force on Life and the Law. *Assisted reproductive technologies*. New York: The New York State Task Force on Life and the Law, 1998:165-169.
18. Kuppermann M, Nease RF, Learman LA, et al. Procedure-related miscarriages and Down syndrome-affected births: implications for prenatal testing based on women's preferences. *Obstet Gynecol* 2000;96(4):511-516.
19. Eller DP, Patterson CA, Webb GW. Maternal and fetal implications of anticonvulsant therapy during pregnancy. *Obstet Gynecol Clin* 1997;24:523-534.
20. Jos PH, Perlmutter M, Marshall MF. Substance abuse during pregnancy: clinical and public health approaches. *J Law Med Ethics* 2003;31:340-350.
21. Harris LJ, Paltrow L. The status of pregnant women and fetuses in U.S. criminal law. *JAMA* 2003;289:1697-1699.
22. Johnsen DE. Maternal-fetal relationship: legal and regulatory issues. In: Reich WT, ed. *Encyclopedia of bioethics*, Revised ed. New York: Simon & Schuster Macmillan, 1995: 1413-1418.
23. Chavkin W. Mandatory treatment for drug use during pregnancy. *JAMA* 1991;266:1556-1561.
24. Board of Trustees AMA. Legal interventions during pregnancy: court-ordered medical treatments and legal penalties for potentially harmful behavior by pregnant women. *JAMA* 1990;264:2663-2670.

25. Curran WJ. Court-ordered cesarean sections receive judicial defeat. *N Engl J Med* 1990;323:489-492.
26. Levy JK. Jehovah's Witnesses, pregnancy, and blood transfusions: a paradigm for the autonomy of all pregnant women. *J Law Med Ethics* 1999;27:171-189.
27. Goldblatt AD. Commentary: no more jurisdiction over Jehovah. *J Law Med Ethics* 1999;27:190-193.
28. Nelson LJ, Milliken N. Compelled medical treatment of pregnant women: life, liberty and law in conflict. *JAMA* 1988;259:1060-1066.
29. The New York State Task Force on Life and the Law. *Assisted reproductive technologies*. New York: The New York State Task Force on Life and the Law, 1998:177-213.
30. The President's Council on Bioethics. *Reproduction and responsibility: the regulation of new biotechnologies*. Washington: The President's Council on Bioethics, 2004.
31. Bibby J, Boyd N, Redman C, et al. Consent for vaginal examination by students on anaesthetised patients (letter). *Lancet* 1988;2(8620):1150.
32. Cal Bus & Prof Code §2281 (2003).

ANNOTATED BIBLIOGRAPHY

1. The New York State Task Force on Life and the Law. *Assisted reproductive technologies*. New York: The New York State Task Force on Life and the Law, 1998.
The President's Council on Bioethics. *Reproduction and responsibility: the regulation of new biotechnologies*. Washington: The President's Council on Bioethics, 2004.
Two works that contain ethical and policy analyses regarding assisted reproductive technologies.
2. Dickenson DL, Fulford KWM. *Ethical issues in maternal-fetal medicine*. New York: Cambridge University Press, 2002.
Discusses ethical issues in obstetrics from a feminist and British perspective.
3. McCullough LB, Chervenak FA. *Ethics in obstetrics and gynecology*. New York: Oxford University Press, 1994.
Monograph with a philosophical orientation on ethical issues in obstetrics and gynecology.
4. Minkoff H, Chervenak FA. Elective primary cesarean delivery. *N Engl J Med* 2003;348:298-302.
Argues that elective cesarean delivery at term is a medically and ethically acceptable option.
5. Jos PH, Perlmutter M, Marshall MF. Substance abuse during pregnancy: clinical and public health approaches. *J Law Med Ethics* 2003;31:340-350.
Analysis of ethical and legal issues regarding substance abuse during pregnancy.

Ethical Issues in Psychiatry

Some patients with severe psychiatric illness might cause serious harm to themselves and others, but they might not be capable of making informed decisions about health care or controlling their behavior. Effective treatment of the psychiatric illness might restore their decision-making capacity and control over their actions. Rather than respect their choices, physicians need to protect such nonautonomous patients against the consequences of their decisions and actions.

HOW ARE ETHICAL ISSUES IN PSYCHIATRY DIFFERENT?

SEVERE PSYCHIATRIC ILLNESS MIGHT IMPAIR THE PATIENT'S AUTONOMY

Patients with severe psychiatric illness might be unable to make informed decisions, care for themselves, distinguish right from wrong, or control their thoughts, impulses, and actions. They might have so little insight into illness that they are not considered morally or legally responsible for their actions. When their illness is severe, such patients might have different values, preferences, and judgments than when their illness is treated.

TREATMENT MIGHT RESTORE THE PATIENT'S AUTONOMY

Treatment of the underlying psychiatric illness often restores the patient's decision-making capacity and control over his or her behavior. Thus, a short-term infringement on the patient's freedom, such as involuntary hospitalization, might restore the patient's autonomy in the long term.

PHYSICIANS HAVE A UNIQUE OPPORTUNITY TO PREVENT SERIOUS HARM

Physicians are in a unique position to identify patients who are rendered nonautonomous by psychiatric illness, to protect them from harm, and to prevent harm to third parties. Society therefore has authorized physicians to intervene primarily to protect third parties from harm and also to help such patients obtain treatment.

PSYCHIATRIC THERAPIES RAISE ETHICAL CONCERNS

By altering how people think and feel, effective psychiatric medications might change a person's personality and identity. Some patients complain that medication transforms them into people who are no longer their true selves. Some patients even say that they would rather live with mild symptoms than take medications that alter their brain and their essential characteristics. In contrast, others believe that effective psychiatric therapies, by removing delusions, disturbed thinking, mood

Ethical Issue

disorders, and use of selectiveness to try to improve

Involuntary concerns involuntarily institutions a

CONFIDENTIALITY

In therapy patients respect privacy seek care for protects patients even if their laws, give signed to disclose th

ACCESS TO CARE

Despite recent problems, many restrict the insured, and present prob them to obtain

INVOLUNTARY

Involuntary competency. Because carefully just

RATIONALITY

Intervention of controlling Depriving self (2). After they choose to kill

STANDARDS

Criteria for because of i

- dangerous
- unable to
- dangerous

In addition, their condition laws the real danger to s

disorders, and other undesired characteristics, restore a person's true self. Still others criticize the use of selective serotonin reuptake inhibitors by persons who do not have serious psychiatric illness to try to improve their mood, confidence, or social functioning (1). To these critics self-improvement and accomplishment should result from hard work, not medications.

Involuntary psychiatric interventions, such as forced hospitalization, present even stronger ethical concerns because they deprive patients of liberty. In the past many psychiatric patients were involuntarily subjected to extreme measures, such as lengthy confinement in inhumane mental institutions and psychosurgery.

CONFIDENTIALITY ENCOURAGES THERAPY

In therapy patients reveal their innermost emotions, fears, and fantasies. Maintaining confidentiality respects the personal and sensitive nature of such information and encourages patients to seek care for mental illness and to be candid with physicians. In addition, confidentiality protects patients from stigma and discrimination, which patients with psychiatric illness might face even if their disease is in remission. Recent federal privacy regulations, as well as some state laws, give special protection to psychotherapy notes by requiring specific patient authorization to disclose them.

ACCESS TO PSYCHIATRIC CARE

Despite recent efforts to achieve parity between insurance coverage for medical and psychiatric problems, many patients have limited access to mental health care. Managed care plans often restrict the therapy's frequency or duration. Many patients with severe psychiatric illness are uninsured, and public mental health services are underfunded. Finally, such patients might have concurrent problems, such as homelessness, alcoholism, or substance abuse, that make it difficult for them to obtain care.

INVOLUNTARY PSYCHIATRIC COMMITMENT

Involuntary commitment is a dramatic exception to the ethical guideline of respecting people's liberty. Because it infringes on freedom so profoundly, involuntary psychiatric commitment must be carefully justified.

RATIONALE FOR INVOLUNTARY COMMITMENT

Intervention is warranted to prevent persons who are incapable of making informed decisions and of controlling their actions from causing serious, irreversible harm to themselves or to others. Depriving such patients of their liberty for a short time might allow them to regain their autonomy (2). After their depression, bipolar disorder, or schizophrenia is treated, most patients no longer choose to kill themselves or harm others.

STANDARDS FOR INVOLUNTARY COMMITMENT

Criteria for involuntary commitment differ among states but typically require that patients be, because of mental illness,

- dangerous to themselves—for example, suicidal, or
- unable to care for themselves—for example, unable to provide food, clothing, and shelter, or
- dangerous to others—for example, through a threat, an attempt, or an overt act of harm.

In addition, patients in several states may be involuntarily committed if a severe deterioration in their condition is likely without treatment and they cannot give consent to treatment. Under such laws the rationale for commitment is the patient's need for treatment rather than the patient's danger to self or others (2).

PROCEDURES FOR INVOLUNTARY COMMITMENT

Because involuntary commitment procedures vary across the states, physicians need to be familiar with the law in their states. The following provisions are typical. Initially, patients may be held against their will on an emergency basis for brief periods (typically a few days). During an emergency patients can also be treated against their will to prevent serious physical injury to themselves or others or, in some states, to prevent an irreversible deterioration of their condition. A judicial hearing must be held to determine whether the patient may be confined for a longer period.

Legal hearings are time consuming, and many physicians believe that they are an unwarranted intrusion of the legal system into medical practice. However, many laypeople have a sharply different perspective. Because involuntary psychiatric hospitalization is a serious deprivation of liberty and has been abused in the past, the public demands rigorous safeguards.

Physicians might threaten to initiate commitment proceedings unless the patient "voluntarily" consents to hospitalization. This practice is coercive and ethically questionable (2). Voluntary hospitalization helps physicians by reducing paperwork and eliminating the need for a judicial hearing. However, patients might not realize that by agreeing to voluntary hospitalization, they are waiving their right to a judicial hearing to determine whether commitment is appropriate. A more respectful strategy is to first tell patients that plans for involuntary hospitalization will be instituted and explain their right to a judicial hearing. After patients understand the commitment procedures, they may be offered an opportunity to sign into the hospital voluntarily (2).

OUTPATIENT COMMITMENT AND INVOLUNTARY TREATMENT

In many states patients with psychiatric illness can be subjected to involuntary outpatient treatment if they are at serious risk for relapse because of nonadherence to treatment (3). Such persons can be ordered to undergo outpatient treatment even though they are currently not gravely disabled or violent. Recent highly publicized cases of violence perpetrated by psychiatric patients have sparked interest in outpatient commitment. The rationale for outpatient commitment is to prevent persons from lapsing again into a cycle of deterioration and involuntary hospitalization (4,5). Such mandatory treatment may be carried out in several ways (4,6). It may be a condition of obtaining housing and social service payments. Courts may order it as a condition of avoiding jail or inpatient commitments. Advocates argue that mandatory outpatient treatment is more humane and less restrictive than repeated involuntary hospitalizations. Critics contend, however, that such programs divert attention and resources from the underlying problem of inadequate outpatient services, restrict patient freedom, undermine the voluntary delivery of ambulatory psychiatric care, and deter patients from seeking mental health care (7). Furthermore, critics charge that there is no rigorous evidence that such programs improve public safety.

Outpatient commitment is controversial because two strong ethical guidelines are in conflict. On the one hand, psychiatrists should respect patients who are still competent to make medical decisions by accepting their decisions and by not coercing them. On the other hand, psychiatrists should also intervene to prevent a high likelihood of serious harm to patients, particularly if they can prevent the patient from relapsing into a state of diminished autonomy. The issue is complicated because limited access to outpatient psychiatric care might make less restrictive alternatives impractical.

SUICIDAL PATIENTS

When patients attempt or threaten suicide, physicians have an ethical obligation to intervene. It is essential for physicians to understand the rationale for suicide intervention and to be able to assess the seriousness of suicide threats.

RATIONALE FOR SUICIDE INTERVENTION

The ethical justification for suicide intervention is preventing serious, irreversible harm to persons with impaired decision-making capacity. Suicidal patients are almost always impaired by severe depression or other severe mental illness (8). Their actions therefore are not autonomous choices

but rather ;
treat the u
effectivene
10% to 20%

Even st
onomous]
to restrict

Interv
ing assista
to call for
To varying
while still
who are th
intervene t
capacity is
as long as

Physici
mitting sui
means and
sion-makin
The ethics
(see Chapt

WHEN IS

Many peop
involuntary
measures, ;
patients tru

When p
tions to del
cide will ;
unfounded
ment. Man
physician.

The foll
selves (2,1

- Persons
carry out
- Similarly
- unlikely,
- Persons
- Persons

MITIGATI

When suic
mitted ther
therapy dif
stress share
shame if y
pressed; th
demonstrat
ness, and re

ed to be familiar
its may be held
During an emer-
y to themselves
ition. A judicial
r period.

an unwarranted
re a sharply dif-
privation of lib-

nt "voluntarily"

1. Voluntary hos-
a judicial hear-
zation, they are
ropriate. A more
will be instituted
nent procedures,

patient treatment
persons can be
disabled or vio-
nts have sparked
prevent persons
(5). Such manda-
obtaining housing
or inpatient com-
and less restric-
programs divert
services, restrict
care, and deter
ere is no rigorous

as are in conflict.
to make medical
and, psychiatrists
particularly if they
issue is compli-
cative alternatives

to intervene. It is
to be able to assess

le harm to persons
mpaired by severe
tonomous choices

but rather are the product of their mental illness. Interventions to prevent suicide provide time to treat the underlying mental illness or let it enter a remission. Empirical studies demonstrate the effectiveness of suicide prevention. If persons are prevented from committing suicide, only about 10% to 20% subsequently kill themselves (8).

Even strong proponents of patient autonomy recognize the need to intervene to prevent nonautonomous persons from seriously harming themselves (9). In contrast, it is ethically problematical to restrict the liberty of autonomous persons in order to prevent them from harming themselves.

Interventions to prevent suicide include arranging for voluntary psychiatric treatment, mobilizing assistance from family and friends, removing the means of suicide, getting patients to promise to call for help before they take their lives, and, as a last resort, imposing involuntary commitment. To varying degrees, these interventions restrict patient liberty. Infringements should be minimized while still protecting the patient from harm. In some cases it might be unclear whether patients who are threatening suicide are making an autonomous decision or not. It is ethically prudent to intervene temporarily to ascertain if the threat is serious and if the patient's decision-making capacity is impaired. If involuntary commitment is deemed necessary, it should be continued only as long as necessary to protect the patient.

Physicians need to appreciate that they do not have the power to prevent all patients from committing suicide. After discharge, patients who are determined to kill themselves can find the means and opportunity to do so. In addition, some patients with terminal illnesses, whose decision-making capacity is unimpaired, might make a deliberate and firm decision to end their lives. The ethics of so-called "rational suicide," particularly physician-assisted suicide, is hotly debated (see Chapter 19).

WHEN IS A PATIENT SUICIDAL?

Many people make suicidal gestures that, although representing a "cry for help," might not warrant involuntary commitment. Because such persons can be successfully treated through less restrictive measures, such as outpatient care or voluntary hospitalization, physicians must determine which patients truly need involuntary hospitalization.

When patients are severely depressed or mention suicide, physicians should ask specific questions to determine the likelihood of a serious suicide attempt. Fears that raising the topic of suicide will suggest it to depressed patients or will encourage persons to kill themselves are unfounded and deter physicians from gathering crucial information and initiating effective treatment. Many depressed patients feel relieved to discuss suicide with a caring and nonjudgmental physician.

The following are persons who are more likely to attempt suicide or to succeed in killing themselves (2,10).

- Persons who have an intent to commit suicide, a specific plan for doing so, and the means to carry out the plan. Access to lethal and violent means of suicide indicates particularly high risk. Similarly, it is more serious when the proposed method of the suicide attempt makes rescue unlikely, as when patients have arranged to be alone for an extended period.
- Persons who have made preparations, such as giving away possessions or saying good-bye.
- Persons who view their situation as hopeless or have ideas of reuniting with a deceased person.

MITIGATING THE ADVERSE CONSEQUENCES OF INVOLUNTARY HOSPITALIZATION

When suicidal patients are involuntarily hospitalized, they might view the physicians who committed them as adversaries who can no longer be trusted. Such feelings might make psychiatric therapy difficult. Physicians should try to minimize the confrontational aspects of the situation and stress shared therapeutic goals. An experienced psychiatrist has suggested saying: "It would be a shame if you killed yourself while your depression clouded your judgment. Let's get you undepressed; then, if you still want to kill yourself, I know I can't stop you (2)." Such a statement demonstrates concern, suggests that therapy might effectively lead to remission of the mental illness, and reassures patients that ultimately they are in control.

PATIENTS WHO ARE DANGEROUS TO OTHERS

Patients with serious psychiatric illness might tell physicians about plans to kill or injure third parties, actual attempts, or overt acts of harm. Thus, the physician might be in a unique position to prevent serious harm to the threatened person. Social norms and criminal sanctions might not deter psychiatric patients who cannot control their violent impulses. In this situation the landmark Tarasoff case established that confidentiality should be overridden in order to prevent serious harm to third parties (11).

THE TARASOFF CASE AND THE DUTY TO PREVENT HARM

A university student, Prosenjit Poddar, confided to his psychologist that he was planning to kill a woman, readily identifiable as Tatiana Tarasoff, who had rejected him romantically. The therapist and his superiors at the student health service decided that Poddar should be committed involuntarily and asked the campus police to detain him. The police did so but released him because he appeared rational. The director of psychiatry ordered therapy notes and correspondence with the police destroyed and ordered no action to place Poddar under involuntary detention. Subsequently Poddar went to Tarasoff's home and stabbed her to death.

In a suit by Tarasoff's parents, the California Supreme Court ruled that a therapist who determines, or should have determined, that the patient presents "a serious danger of violence to another" has a "duty to exercise reasonable care to protect others against dangers emanating from the patient's illness (11)." Thus, the court found a duty to protect potential victims, not just warn them. The court rejected the defendant's arguments that the defendant had owed no duty of care to Tarasoff, that predictions of violence by psychiatric patients are inherently inaccurate, and that confidentiality is essential to psychotherapy. The court ruled that the special relationship between patients and their doctors or psychotherapists supports "affirmative duties for the benefit of third persons." In this case fallibility of predications of violence was not an issue because the therapists had determined that Poddar was dangerous. Furthermore, the confidentiality of psychotherapy communication must be balanced against the need to avert danger to others. "The protective privilege ends where the public peril begins (11)."

Therapists feared that the decision would undermine the doctor-patient relationship. They predicted that patients would be deterred from seeking mental health services and disclosing their violent thoughts, that warning potential victims would be ineffective, and that issuing a warning would effectively end therapy with a patient (12). However, these effects have not occurred to any significant degree (12).

Most states require therapists to protect identifiable persons threatened with serious violence by psychiatric patients (12). Generally, the duty is limited to identifiable patients and actual threats. In most states therapists can meet this legal duty by warning the potential victim or the police or by hospitalizing the patient (12).

STEPS TO PREVENT HARM

The duty to prevent harm to potential victims of psychiatric patients requires several steps (13,14). First, the physician needs to evaluate the threat of violence. As with asking about suicide, physicians need to appreciate that asking about violence does not give patients the idea of harming others or encourage them to do so. It might be useful to ask whether the patient has ever seriously injured another person or has ever thought about harming someone else (14).

Predictions of violence by physicians can be quite inaccurate. In one study 53% of patients whom clinicians predicted would be violent in fact committed violent acts over the subsequent 6 months; in comparison, 36% of patients whose psychiatrists had no concerns about violence committed violent acts (15). Violence was more serious in those patients whose psychiatrists had predicted would be violent. For women, however, the accuracy of predictions of violence was no greater than that expected by chance alone. Doctors need to do the best they can within the limits of clinical judgment. The standard of care is what a reasonable physician would do under the circumstances.

After determining that the threat of violence is severe and probable, the physician must decide how to respond. A number of actions might protect the victim, such as changing the patient's

medication
voluntarily
fying the
Physician
required
might he
the threat
finding of
beginning
tions in w

REFUSAL

Patients v
tent to re
tasks, a p
medication
cized as
severely i
view shor
a lesser in
treatment.

Noneth
committed
accomplis
patients at
cians. Ma
their brain
unilateral.

The eth
(see Chapt
third parti
administra
long run.
(and often

Several
ized psych
involuntari
tent to ma
patient is r

The pat
refusal of
the decisio
with major
(19). They
side effect
treatment i
ing is wro
give seemi
because th
of treatment

Empiric
of inpatient
because of
tions in 35'
Cases were

injure third parties; position to pre-empt might not deter landmark Tarasoff serious harm to

planning to kill a family. The therapist admitted involuntarily committed him because he had evidence with the police. Subsequently

therapist who deterred of violence to emanating from patients, not just warn the duty of care to be accurate, and that the relationship between the benefit of third parties use the therapists of psychotherapy as protective privilege

relationship. They pre-empted closing their violence by issuing a warning that occurred to any

serious violence by the actual threats. In the police or by

several steps (13,14). But suicide, physicians of harming others has ever seriously

of patients whom frequent 6 months; in committed violent predicted would be greater than that of clinical judgment. In cases.

physician must decide regarding the patient's

medications, increasing the frequency of therapy sessions, attempting to hospitalize the patient voluntarily or committing the patient involuntarily, having the patient give up weapons, and notifying the police (14). The law in many states specifically requires warning the threatened victim. Physicians should notify patients before they override confidentiality and explain why they are required to do so (14). Discussing with patients threats against third parties as part of therapy might help maintain a therapeutic relationship (16). Patients might permit the physician to warn the threatened person (2). Many patients are ambivalent about violence and might welcome help in finding other ways to express their emotions or deal with interpersonal conflicts. In addition, when beginning therapy with patients who have a history of violence physicians might discuss the situations in which confidentiality may be overridden (2).

REFUSAL OF PSYCHIATRIC TREATMENT

Patients who are involuntarily committed to psychiatric institutions might still be deemed competent to refuse psychiatric treatment. Because competency is determined with regard to specific tasks, a patient who is not competent to refuse commitment might still be competent to refuse medications. Confining patients but not treating them with effective medications has been criticized as "rotting with their rights on (17)." To critics it is cruel and pointless to withhold from severely impaired patients the very treatments that are likely to restore their autonomy. In this view short-term involuntary treatment, which might improve the underlying psychiatric illness, is a lesser infringement on the patient's freedom than prolonged involuntary hospitalization without treatment.

Nonetheless, many states have made it more difficult to administer treatments to involuntarily committed psychiatric patients. The rationale is that confinement without treatment can sometimes accomplish involuntary hospitalization's goal—prevention of harm to self or others. In addition, patients and the public might view psychiatric therapies' risks and benefits differently from physicians. Many psychiatric patients reject drugs because of side effects or because medications alter their brain and personality. Furthermore, past abuses have led the public to mistrust physicians' unilateral judgments that treatment is beneficial and necessary.

The ethical guideline of preventing harm has more moral force than the guideline of doing good (see Chapter 4). Thus, the obligation to prevent harms to nonautonomous psychiatric patients or to third parties is stronger than the duty to help psychiatric patients recover from their illness. Forced administration of medications to unwilling patients is intrusive, inhumane, and impractical in the long run. Even if psychiatric medications were forcibly administered to inpatients, patients can (and often do) discontinue therapies after discharge.

Several states have procedures to deal with such refusals of treatment by involuntarily hospitalized psychiatric patients. These states require a court hearing if a psychiatric patient who has been involuntarily committed refuses treatment (2). The court determines whether the patient is competent to make an informed decision to refuse treatment. If so, the refusal must be honored. If the patient is not competent, the court decides whether the treatment will be provided.

The patient's capacity to make informed decisions therefore is crucial to whether the patient's refusal of therapy will be respected. Chapter 10 discussed decision-making capacity. Assessing the decision-making capacity of psychiatric patients might be particularly difficult (18). People with major depression might underestimate the benefits of treatment and overestimate the risks (19). They might be convinced that the treatment will fail or that they will experience a serious side effect of therapy. Depressed patients might also believe that they deserve to suffer and that treatment might interfere with such suffering. Similarly, manic patients might believe that nothing is wrong with them and therefore reject treatment. Both depressed and manic patients can give seemingly logical reasons for their decisions yet be incapable of making informed decisions because they hold false premises about medical care and inaccurately assess the benefits and risks of treatment.

Empirical studies have described refusals of antipsychotic medications. In one study only 7% of inpatients refused antipsychotic medication for longer than 24 hours (20). Patients refused because of psychotic or idiosyncratic thought processes in 30% of cases, side effects of medications in 35%, denial of mental illness in 21%, and alleged ineffectiveness of medications in 12%. Cases were resolved in several ways. In 50% of cases the patient eventually took medication

voluntarily. Typically, the nursing staff, psychiatrists, or family persuaded the patient. In 23% of cases either the psychiatrist discontinued antipsychotic drugs or the patient was discharged without medication—that is, the physician probably did not consider these medications essential. Finally, in 18% of cases the psychiatrists obtained a court order for involuntary administration of the medication. In all the cases that went to court, the judge authorized involuntary treatment.

REFUSAL OF MEDICAL TREATMENT BY PSYCHIATRIC PATIENTS

Patients with serious psychiatric illness might refuse recommended therapy for concurrent medical problems. As with other patients who refuse interventions, physicians should ask whether the patient has intact decision-making capacity. A psychiatric diagnosis *per se* does not imply that a patient lacks the capacity to make an informed decision about treatment. A competent patient's refusal should be respected if attempts at persuasion are unsuccessful. If the patient lacks decision-making capacity, decisions should be based on advance directives or made by surrogates (see Chapters 12 and 13).

Decisions might be especially perplexing when psychiatric patients who lack decision-making capacity actively resist treatment that is clearly in their best interests. Forced treatment might be difficult to carry out if patients actively protest or resist. It might also be counterproductive because issues of control and independence might be problems that patients need to resolve. Overriding patients' refusal might make it more difficult for them to take responsibility and control of other aspects of their lives. Finally, the possibility of forced treatment is illusory. In a structured inpatient setting, the staff might, through cajoling, negotiation, and threats, be able to ensure that the patient is taking the medicine. For example, health care workers might threaten to withhold visiting privileges, outings, or cigarettes. However, the patient might discontinue medicines after discharge.

In conclusion, when psychiatric patients are suicidal, unable to care for themselves, or are dangerous to others, physicians have ethical as well as legal obligations to prevent harm. This obligation might override the ethical guidelines of respecting patient autonomy and maintaining confidentiality. In fulfilling this duty, physicians also need to use their clinical skills and judgment to encourage effective treatment for the underlying psychiatric disorders.

REFERENCES

1. The President's Council on Bioethics. *Beyond therapy: biotechnology and the pursuit of happiness*. Washington: The President's Council on Bioethics, 2003.
2. Appelbaum PS, Gutheil TG. *Clinical handbook of psychiatry and the law*, 2nd ed. Baltimore: Williams & Wilkins, 1991.
3. Swartz MS, Monahan J. Special section on involuntary outpatient commitment: introduction. *Psychiatr Serv* 2001;52(3):323-324.
4. Monahan J, Bonnie RJ, Appelbaum PS, et al. Mandated community treatment: beyond outpatient commitment. *Psychiatr Serv* 2001;52(9):1198-1205.
5. Torrey EF, Zdanowicz M. Outpatient commitment: what, why, and for whom. *Psychiatr Serv* 2001;52(3):337-341.
6. Monahan J, Swartz M, Bonnie RJ. Mandated treatment in the community for people with mental disorders. *Health Aff (Millwood)* 2003;22(5):28-38.
7. Allen M, Smith VF. Opening pandora's box: the practical and legal dangers of involuntary outpatient commitment. *Psychiatr Serv* 2001;52(3):342-346.
8. Miller RD. Need-for-treatment criteria for involuntary civil commitment: impact in practice. *Am J Psychiatry* 1992;149:1380-1384.
9. Beauchamp TL, Childress JF. *Principles of biomedical ethics*, 4th ed. New York: Oxford University Press, 1994: 271-287.
10. Blumenthal SJ. Suicide: a guide to risk factors, assessment, and treatment of suicidal patients. *Med Clin North Am* 1988;72:937-971.
11. *Tarasoff v. Regents of the University of California*. 551 P2d 334 (Cal 1976).
12. Appelbaum PS. *Almost a revolution: mental health law and the limits of change*. New York: Oxford University Press, 1994:71-113.
13. Appelbaum PS, Zonana H, Bonnie R, et al. Statutory approaches to limiting psychiatrists' liability for their patients' violent acts. *Am J Psychiatry* 1989;146:821-828.
14. Anfang SA, Appelbaum PS. Twenty years after Tarasoff: Reviewing the duty to protect. *Harv Rev Psychiatry* 1996;4:67-76.
15. Lidz C, Mulvey EP, Gardner W. The accuracy of predictions of violence to others. *JAMA* 1993;269:1007-1011.
16. Simon RI. Clinical approaches to the duty to warn and protect endangered third parties. *Clinical psychiatry and the law*. Washington: American Psychiatric Press, Inc, 1987:307-336.

nt. In 23% of
charged with-
ons essential.
inistration of
treatment.

urrent medical
: whether the
t imply that a
tent patient's
cks decision-
urrogates (see

ision-making
ent might be
active because
e. Overriding
ntrol of other
ured inpatient
at the patient
visiting privi-
discharge.
s, or are dan-
. This obliga-
maintaining
and judgment

ss. Washington:

iams & Wilkins,

. *Psychiatr Serv*

nt commitment.

,52(3):337-341.
ental disorders.

patient commit-

Am J Psychiatry

sity Press, 1994:

Med Clin North

xford University

or their patients'

Rev Psychiatry

269:1007-1011.
l psychiatry and

17. Appelbaum PS, Gutheil TG. "Rotting with their rights on": constitutional theory and clinical reality in drug refusal by psychiatric patients. *Bull Am Acad Psychiatry Law* 1979;7:306-315.
18. Gutheil TG, Bursztajn HJ, Brodsky A, et al. Affective disorders, competence, and decision making. *Decision making in psychiatry and the law*, 2nd ed. Baltimore: Williams & Wilkins, 1991:153-170.
19. Grisso T, Appelbaum P. *Assessing competence to consent to treatment: a guide for physicians and other health professionals*. New York: Oxford University Press, 1998:49-51.
20. Hoge SK, Appelbaum PS, Lawlor T. A prospective, multicenter study of patients' refusal of antipsychotic medication. *Arch Gen Psychiatry* 1990;47:949-956.

ANNOTATED BIBLIOGRAPHY

1. Gutheil TG, Appelbaum PS. *Clinical handbook of psychiatry and the law*, 3rd ed. Philadelphia: Lippincott Williams & Wilkins, 2000.
Excellent book on ethical and legal issues regarding psychiatric patients. Contains practical clinical advice on managing patients with severe psychiatric disorders.
2. Appelbaum PS. *Almost a revolution: mental health law and the limits of change*. New York: Oxford University Press, 1994.
Lucid discussion of the ethical and policy issues regarding involuntary commitment and treatment.
3. Dickenson D, Fulford KWM. *Two minds: a casebook of psychiatric ethics*. New York: Oxford University Press, 2000.
Case discussions of ethical issues in psychiatric diagnosis, symptom interpretation, and social control from a British perspective.
4. The President's Council on Bioethics. *Beyond therapy: biotechnology and the pursuit of happiness*. Washington: The President's Council on Bioethics, 2003.
Critique of the widespread use of psychiatric medications for enhancement rather than for major psychiatric illness.

Ethical Issues in Organ Transplantation

Kidney, liver, heart, and lung transplantation can allow patients with end-stage disease to return to active lives. In organ donation interventions are performed on one person in order to benefit another. Thus, consent for donation and preventing harm to donors are essential to maintain public trust that physicians never compromise one patient's care to benefit someone else. The need for organ transplantation far exceeds the supply of donated organs; in May 2004 more than 85,000 people were on waiting lists for transplants. Thus, difficult decisions about allocating donated organs cannot be avoided. This chapter discusses the donation of organs, the selection of recipients, and the cost of transplantation.

DONATION OF CADAVERIC ORGANS

ETHICAL CONCERNS ABOUT CADAVERIC DONATION

Harm to Donors

At the onset, concerns were raised that cadaveric organ transplantation hastened or caused the donor's death. Criteria were developed for determining death in patients whose brains had ceased to function but whose hearts were still beating (*see* Chapter 21). Misunderstandings about brain death persist, and many people do not understand why organs may not be harvested from anencephalic infants and persons in a persistent vegetative state.

Conflicts of Interest

Because of concerns that potential organ donors might receive suboptimal care, decisions about the potential donor's care must be separate from decisions about procurement and transplantation. The physician for the potential donor may not be part of the transplantation team. Also, in the United States payments for donation are prohibited to prevent abuse and exploitation of potential donors.

The Autonomy of Organ Donors

Some people would not want to be organ donors, and their wishes need to be respected. It is controversial how much evidence of a donor's consent or refusal is required and whether surviving relatives may decline to donate even if the patient would have wanted to be a donor.

THE CURRENT SYSTEM FOR CADAVERIC DONATION

The United States has a voluntary altruistic system for organ donation. The Uniform Anatomical Gift Act allows people to use an organ donor card to grant permission to use their organs for transplantation after their death. This card is usually attached to a person's driver's license. However,

few Americans have signed such cards. One reason is fear that persons who have agreed to organ donation will receive suboptimal care (1). Although the donor card has legal authority, in practice permission for organ donation is sought from the next of kin after the donor's death (2). Hospitals must report all inpatient deaths to local organ procurement organizations, which contact eligible families to request donation (3).

Only about 50% of relatives of patients with brain death give permission for organ donation (1). Many families do not understand the concept of brain death, and some perceive the organ procurement process as insensitive (1). Some cultures reject organ donation (4,5). For instance, some Asian or Latino families believe that bodies or spirits can suffer after death if organs are removed.

NONHEART-BEATING CADAVER DONORS

Most cadaver donors are declared dead by brain criteria and have effective circulation until the harvesting of organs. A few donors are declared dead by cardiorespiratory criteria (1,6,7). In one approach, donors are terminal patients whose life-sustaining interventions will be withdrawn. They are transported to the operating room, where life support is withdrawn, death is declared using cardiorespiratory criteria, and organs are promptly retrieved (1,6-8). This approach has been criticized because relatives might not have sufficient opportunity to be with dying patients. In addition, anticoagulants and vasodilators administered to preserve the organs might hasten or cause death. In a second approach, donors are patients in whom cardiopulmonary resuscitation (CPR) fails or who are dead on arrival in the emergency department. Catheters are inserted into patients immediately after death is pronounced and organs are perfused to keep them viable (6,7). Later, physicians seek permission for transplantation from relatives. However, consent is not obtained for insertion of catheters and perfusion of organs (1,7). Surveys show that the public strongly objects to such procedures being carried out without permission.

PROPOSALS TO INCREASE THE DONATION OF CADAVERIC ORGANS

Many proposals have been made to increase cadaveric organs donation, and some have been adopted in other countries. However, some of these proposals might undermine public trust in transplantation, which in the long term might make people less willing to donate.

Mandated Choice

Persons would be required to state their preferences about organ donation when renewing drivers' licenses or filing income taxes (9). This requirement would relieve relatives of the stress of making decisions about donation. In surveys most Americans support this policy.

Following Donor Cards

Physicians would retrieve organs from people who had signed donor cards even if the next of kin objects. Legally, this policy would merely implement existing statutes. Ethically, it is consistent with respecting patient autonomy and advance directives. However, some family members might feel outraged if organs are harvested over their objections.

Presumed Consent

Currently, organs are harvested only if the patient or family has given explicit consent. Under this proposed policy, organs would be harvested unless the patient or family specifically objects (10). However, 52% of respondents in a U.S. survey disapproved of this approach (11).

Financial Incentives for Donation

A regulated market in organs has been proposed to increase the supply of organs (12). Critics charge that such a market would undermine altruism, treat the human body as a commodity, and result in exploitation, fraud, or coercion, particularly in underdeveloped countries (13,14). Furthermore, commercially motivated renal transplantation in developing countries might pose risks to recipients because of a significantly higher rate of human immunodeficiency virus (HIV) and hepatitis B infection (15). In the United States buying and selling of organs is illegal because of

objections to commodifying vital organs and concerns about exploitation. However, one state provides partial burial expenses for cadaveric donors. In addition, proposals have been made to give living organ donors incentives, such as medical leave, life insurance, and highest priority for transplantation if they should need it (16). Proponents distinguish these modest incentives and tokens of appreciation from cash payments.

DONATION OF ORGANS FROM LIVE DONORS

Transplantation of kidneys and portions of liver and lung from live donors is increasing. In 2002, 43% of kidney transplants were from living donors. Live donors include both "emotionally related donors"—such as relatives, friends, and coworkers (17)—and strangers. Donation from strangers is technically feasible because human leukocyte antigens (HLA) compatibility does not enhance survival of liver and lung transplants and is less important in transplants from living kidney donors than from cadaveric donors. The quality of organs from live donors is higher because of thorough screening and shorter ischemia time compared to cadaveric donors. Transplants from live donors do not delay cadaveric transplants to other patients on the waiting list because the total number of transplants is increased. Hence, persons on the waiting list suffer no adverse consequences.

ETHICAL ISSUES REGARDING LIVE DONATION

Harm to Donors

Surgeons might violate the guideline of "do no harm" when they perform an operation on a healthy person for another person's benefit. The highly publicized death of a living liver donor in New York in 2002 dramatized the grave risks of donation. In addition to serious medical problems such as bile leak, donors suffer pain and lost income.

To limit risks, persons may not serve as living donors if they have medical conditions that significantly increase operative risk or if they have abnormal organ function. In the case of kidney donation, persons are excluded as donors if they have a condition that might impair renal function in the future. To further reduce risk of living liver donation, some have advocated that this procedure be carried out only at experienced centers (18,19).

In many impoverished countries paying live donors is widespread (13). In India living kidney donors said that they were financially worse off after surgery despite having received payments (20). Although some writers have advocated a regulated market to increase the number of organs from living donors, the likelihood of exploitation, coercion, and abuse is a compelling reason to reject such proposals.

Motives of Donors

Donation to relatives and friends is understandable because people are expected to help and care for others with whom they have close relationships. However, donating to a stranger raises concerns. On the one hand, forming a close emotional bond to a stranger in need can be an extraordinary form of altruism and humanitarianism. On the other hand, it can also be driven by a desire for publicity or financial gain, by internal psychological conflicts, or by psychopathology. Thus, offers by strangers to donate need to be carefully reviewed to rule out such problematic motives.

Consent from Donors

Because a live donor undergoes serious risks in order to benefit another person, it is essential that the decision to donate be free and informed. Altruism does not fit a model of rational utilitarian deliberation about personal risks and benefits. The live donor finds a reward in making a sacrifice to benefit someone else. Consent might not be informed because many live donors choose to donate immediately, before they learn of the risks of donation. Also, consent might not be free. Relatives might feel social pressure to donate. Donors might also feel internally compelled to donate.

People commonly base important decisions on emotion rather than reason. Donors should be able to explain their decision to donate, however, in a coherent manner, which takes into account the risks. The donor needs to understand the procedure's risks, even though the donor might give less weight than most people to the possibility of a serious risk. The donor should make a choice

that remain
decision s

The "g
impose re
nary that i
might take
might mal
transplant

Use of
themselves
nary sacri
donors on
donor's in

Confiden

The recipi
donate. F
transplant
feel that
about thei
consent. p
However,
disclose s

THE CUI

Live dona
process e
medically

Some
example.
potential
sure is ju
were kno
condition

SELECT

Because
ficult dec

HISTOR

When dis
able and
to conce
decided t
allocation

Becau
tion proc
the feder
tion with
rules for

The f
tion crite
www.un

that remains stable after the donor receives more information and has time to reflect. Also, the decision should be consistent with the donor's core values.

The "gift of life" through live donation entails obligations and burdens (21). Generally, gifts impose reciprocal obligations and expectations on the recipient. The gift of an organ is so extraordinary that it can never be repaid and might therefore become a "tyranny (21)." A live kidney donor might take a "proprietary interest" in the recipient's life (21). The recipient's sense of indebtedness might make it difficult for him or her to remain independent of the donor. For these reasons, many transplantation programs generally do not reveal the identities of donors and recipients to each other.

Use of children as live donors raises ethical concerns because they cannot give consent for themselves and depend on others to protect their interests. Although adults may make extraordinary sacrifices for others, they may not require children to do so. Hence, children should be live donors only as a last resort if no suitable adult donor can be identified. To assure that a child donor's interests are protected, approval from the courts should be sought.

Confidentiality of Recipient

The recipient might have a medical condition that might affect the potential donor's willingness to donate. For example, the recipient might have a condition such as cancer that might recur in the transplanted organ and reduce the likelihood of long-term success. Moreover, some donors might feel that patients whose liver failure was caused by alcoholic cirrhosis or HIV infection brought about their illnesses through their own actions and choices. According to the principle of informed consent, prospective donors should receive information that is pertinent to their decision to donate. However, patient confidentiality is also important; potential recipients should give permission to disclose such information to potential donors (22).

THE CURRENT SYSTEM FOR LIVE DONATION

Live donors undergo extensive education and medical and psychosocial evaluation (23,24). This process ensures that decisions to donate are informed, free, and altruistic, and that the donor is medically suitable.

Some eligible donors who do not wish to donate might need help in carrying out their wishes—for example, in the face of family pressure to donate. The transplant team might need to say that the potential donor has been ruled out as unsuitable, without providing more specifics. Such nondisclosure is justified because the person might face pressure to donate and recrimination if the true reason were known (21). It is ethically problematic, however, to misrepresent the potential donor's medical condition to provide a reason not to donate (23).

SELECTION OF RECIPIENTS

Because the number of people needing transplants far exceeds the number of donated organs, difficult decisions about allocating organs must be made.

HISTORICAL BACKGROUND

When dialysis was developed in the 1960s, only a limited number of dialysis machines were available and committees ranked candidates according to their perceived social worth (25). Responding to concerns that selection was based on prejudice and unwarranted value judgments, Congress decided to fund dialysis for all patients with end-stage renal disease. In transplantation, however, allocation decisions cannot be avoided because the limiting factor is a lack of organs.

Because people donate cadaveric organs without knowing who will receive them, a fair allocation procedure is essential to maintain public trust in transplantation (14,26). In the United States the federal government and the United Network for Organ Sharing (UNOS), a nonprofit organization with which the government contracts to operate the system for distributing organs, set the rules for allocating cadaveric organs.

The following section discusses general ethical principles for allocating organs. Specific selection criteria are too detailed to be discussed here but can be found on the Web site of the UNOS at www.unos.org. Different considerations receive priority for different organs (27,28).

BENEFICENCE

From a utilitarian perspective, scarce organs should go to those patients who will receive the greatest net medical benefit. Relevant outcomes include the likelihood and duration of survival and the patient's quality of life. Although this criterion appears objective, it involves complex value judgments.

Psychosocial factors such as poor adherence to medical regimens, substance abuse, and lack of family support might compromise outcomes of transplantation. Recent injection drug use and a history of nonadherence are commonly regarded as contraindications to transplantation (29–31). Many physicians consider it pointless to transplant a scarce organ that is very likely to be rejected because of nonadherence to immunosuppressant drugs. Critics, however, contend that psychosocial factors might “cloak biases about race, class, social status, and other factors that, if stated openly, would not be tolerated (26).” Furthermore, such obstacles might be overcome with rehabilitation and psychosocial support (28).

JUSTICE

The guideline that scarce resources should be distributed fairly or equitably is indisputable in the abstract but difficult to specify. Several ways to operationalize equity have been considered.

Time on the Waiting List

The precept of “first-come, first-served” seems intuitively fair if there are no other compelling reasons to distinguish among candidates. However, time on the waiting list can be manipulated by placing patients on the waiting list earlier in the course of illness or at several regional transplantation networks (14,32). Better-educated and wealthier patients are more likely to be on multiple waiting lists.

Medical Need

In liver and heart transplantation, patients who would die soon without transplantation are given priority over more stable patients (33). The rationale is to assist those in greatest need. In 2002 the prioritization system for cadaveric liver transplantation was revised to use a severity of illness score [the Model for End-Stage Liver Disease (MELD) system] based on objective laboratory tests that predict the risk of death while on the waiting list more accurately than clinical judgment does. However, significant geographical disparities remain, with sicker patients in larger organ-procurement areas waiting longer for transplants than patients in smaller organ-procurement areas (34).

Ability to Pay

Transplantation is generally performed only on patients who can pay for it. Medicare covers kidney transplantation for all Americans, and most private insurers and most state Medicaid programs cover liver and heart transplantation (35). Americans who lack health insurance must raise money for transplantation of organs other than kidneys through means such as public appeals.

Allocating organs by ability to pay, although routinely practiced, has been strongly criticized (14). It seems unfair to ask all people, rich and poor alike, to be organ donors if the poor or uninsured would not be eligible recipients. Also, people might be less willing to donate organs if they perceive that the distribution system favors the wealthy.

Previous Transplantation

The success rate in transplanting a second organ after a transplanted organ fails is substantially lower than in first-time transplants (36). The guideline of promise keeping or loyalty is often used to justify retransplantation; having made a commitment to the patient, the surgeons cannot now abandon the patient. Critics contend, however, that retransplantation might be “an obdurate, publicly theatricalized refusal” to accept the inevitable limits of human life and an unwillingness to say “enough is enough (37).”

Citizenship

Should people who are not long-term U.S. residents receive organs harvested in the United States (14)? Particular objections have been directed at foreigners who come to the United States

Ethic

speci
contr

Geog

In res
that c
emph
chang
have
penal
of inc

Ethni

Even
they f
tion, t
transp
kidney
makes
Amer
renal
group
cation
to trar
only s

DIFFE

The et
For re
ing is
is give
highes
becaus
might
greater

PATIE

Patien
tation
tions r
and lo
though
pressic
whethe
no fau
line of
scarce
are giv
have b
ronme
respon
treatm
moral
from h

specifically to obtain a transplant. It seems unfair, however, to exclude foreign nationals who contribute to the U.S. economy and who would be asked to serve as organ donors.

Geographic Location

In response to significant disparities in waiting times for liver transplantation, it has been proposed that organs be allocated on a national basis to those with the greatest medical need, with less emphasis on keeping organs in the geographic area in which they are donated (3). This proposed change would provide more organs to large referral centers, which transplant sicker patients and have better outcomes. However, opponents object that such redistribution is unfair because it penalizes states that make efforts to increase donations and might also worsen outcomes because of increased cold ischemia time (3).

Ethnic Background

Even though African Americans are more likely than Caucasians to develop chronic renal failure, they have less access to renal transplantation. They are less likely to be evaluated for transplantation, to be placed on waiting lists, and to find a suitable donor (38,39). Also, waiting times on transplantation lists are longer for African Americans. The point system for prioritizing cadaveric kidneys gives priority to HLA matching, which improves graft and patient survival. However, this makes it more difficult for African Americans to receive cadaveric kidneys. Although African Americans donate cadaveric kidneys at the same rate as Caucasians, they have a greater need for renal transplantation. Because the prevalence of ABO and HLA antigens differs among ethnic groups, African Americans are less likely to find a highly matched Caucasian donor. Thus, the allocation procedures to maximize benefit through optimal graft survival conflict with equitable access to transplantation. Proposals have been made to modify the point system to increase equity while only slightly increasing renal graft loss (40,41).

DIFFERENCES IN ALLOCATING VARIOUS ORGANS

The ethical guidelines of beneficence and justice are balanced differently for different organs (33). For renal failure, dialysis is an effective alternative to transplantation and the level of HLA matching is a predictor of cadaveric graft survival. Hence, urgency is not considered and HLA matching is given weight. In contrast, in liver failure, because there is no alternative to transplantation, the highest priority is given to patients in the most critical condition. HLA matching is not considered because it has little impact on outcomes for this procedure. These different ethical considerations might conflict. For example, liver recipients with the most urgent need have worse outcomes and greater costs than more stable patients.

PATIENT BEHAVIORS THAT CAUSE DISEASE

Patients with end-stage alcoholic cirrhosis disease initially were not considered for transplantation because it was believed that active drinkers would not take immunosuppressive medications regularly. However, selected alcoholics who receive liver transplantation have short-term and long-term survival rates comparable to those of patients with other liver diseases even though a few recipients have a relapse of alcoholism and are noncompliant with immunosuppression (42). Thus, the issue is not whether such transplantation is medically feasible but whether it should be done. Some argue that patients who develop end-stage liver disease "through no fault of their own" should have higher priority than persons with alcoholism (43). In this line of thinking, patients should be held responsible for behaviors that would deprive others of scarce resources. Others contend that the public might be less willing to donate organs if they are given to alcoholics. On the other hand, restrictions on liver transplantation for alcoholics have been strongly criticized (44). Critics argue that because alcoholism has genetic and environmental components that are beyond the person's control, it would be unfair to hold a patient responsible for it. Moreover, criteria for disqualification are inconsistent and arbitrary and treatment for alcohol dependence is not routinely offered (45). Furthermore, judgments of moral responsibility are not made for other illnesses. For example, smokers are not precluded from heart transplants.

COST OF TRANSPLANTATION

Because of the soaring cost of medical care, the cost effectiveness of organ transplantation cannot be ignored. In 2002 average billed charges for a kidney transplant were \$143,000, for a liver transplant \$314,000, and for a heart transplant \$392,000 (46). The annual costs of follow-up care after transplantation are comparable to the costs of other high-technology medical interventions, such as cancer chemotherapy (35).

The cost of organ transplantation can also be viewed in the context of allocating resources in a health care system that denies many persons access to basic care. Critics charge that "allowing ourselves to become too caught up in such problems as the shortage of transplantable organs while . . . millions of people do not have adequate or even minimally decent care" is "medically and morally untenable (47)."

In summary, although organ transplantation can return patients with end-stage illness to active lives, it raises difficult issues of informed choice in donation and fair allocation of scarce resources. These dilemmas need to be addressed openly in order to maintain public trust in transplantation.

REFERENCES

1. Herdman R, Potts JT. *Non-heart-beating organ transplantation: medical and ethical issues in procurement*. Washington: National Academy Press, 1997.
2. Wendler D, Dickert N. The consent process for cadaveric organ procurement: how does it work? How can it be improved? *JAMA* 2001;285(3):329-333.
3. Committee on Organ Procurement and Transplantation Policy. *Organ procurement and transplantation: assessing current policies and the potential impact of the HHS final rule*. Washington: National Academy Press, 1999.
4. Perkins HS. Cultural differences and ethical issues in the problem of autopsy requests. *Tex Med* 1991;87:72-77.
5. Tolle SW, Bennett WM, Hickam DH, et al. Responsibilities of primary physicians in organ donation. *Ann Intern Med* 1987;106:740-744.
6. Youngner SJ, Arnold RM. Ethical, psychosocial, and public policy implications of procuring organs from non-heart beating cadaver donors. *JAMA* 1993;269:2769-2774.
7. Institute of Medicine. *Non-heart-beating organ transplantation: protocols and practice*. Washington: National Academy Press, 1999.
8. Youngner SJ, Arnold RM, Schapiro R, eds. *The definition of death*. Baltimore: The Johns Hopkins University Press, 1999.
9. Council on Ethical and Judicial Affairs of the American Medical Association. Strategies for cadaveric organ procurement: mandated choice and presumed consent. *JAMA* 1994;272:809-812.
10. Kennedy I, Daar AS, Sells RA, et al. The case for "presumed consent" in organ donation. *Lancet* 1998;351:1650-1652.
11. Kittur DS, Hogan MM, Thukral VK, et al. Incentives for organ donation? *Lancet* 1991;338:1441-1443.
12. Radcliffe-Richards J, Daar AS, Guttmann RD, et al. The case for allowing kidney sales. *Lancet* 1998;352:1950-1952.
13. Scheper-Hughes N. Keeping an eye on the global traffic in human organs. *Lancet* 2003;361(9369):1645-1648.
14. Childress JF. Ethical criteria for procuring and distributing organs for transplantation. *J Health Polit Policy Law* 1989;14:87-113.
15. The Living Non-Related Renal Transplant Study Group. Commercially motivated renal transplantation: results in 540 patients transplanted in India. *Clin Transplant* 1997;11:536-544.
16. Arnold R, Bartlett S, Bernat J, et al. Financial incentives for cadaver organ donation: an ethical reappraisal. *Transplantation* 2002;73(8):1361-1367.
17. Spital A. Ethical and policy issues in altruistic living and cadaveric organ donation. *Clin Transplant* 1997;11:77-87.
18. Cronin DC, Siegler M. Ethical issues in living donor transplantation. *Transplant Proc* 2003;35(3):904-905.
19. Cronin DC, 2nd, Millis JM, Siegler M. Transplantation of liver grafts from living donors into adults—too much, too soon. *N Engl J Med* 2001;344(21):1633-1637.
20. Goyal M, Mehta RL, Schneiderman LJ, et al. Economic and health consequences of selling a kidney in India. *JAMA* 2002;288(13):1589-1593.
21. Fox RC, Swazey JP. *Spare parts*. New York: Oxford University Press, 1992:31-42.
22. Roland ME, Lo B, Braff J, et al. Key clinical, ethical, and policy issues in the evaluation of the safety and effectiveness of solid organ transplantation in HIV-infected patients. *Arch Intern Med* 2003;163(15):1773-1778.
23. Abecassis M, Adams M, Adams P, et al. Consensus statement on the live organ donor. *JAMA* 2000;284(22):2919-2926.
24. Adams PL, Cohen DJ, Danovitch GM, et al. The nondirected live-kidney donor: ethical considerations and practice guidelines: A National Conference Report. *Transplantation* 2002;74(4):582-589.
25. Fox RC, Swazey JP. *The courage to fail: a social view of organ transplants and dialysis*, 2nd ed. Chicago: University of Chicago Press, 1978.
26. Robertson JA. Patient selection for organ transplantation: age, incarceration, family support, and other social factors. *Transplant Proc* 1989;21:3431-3436.

27. UNOS
- 142-16
28. Council
- cation
29. Evans
- of a co
- study: j
30. Evans
- results
- tation s
31. Evans
- of a co
- study: j
32. Sanfilippo
- candida
33. Haupt
- 1997;33
34. Trotter
- organ a
35. Evans
- transpla
36. Ubel PA
- JAMA 1
37. Fox RC
38. Young
39. Epstein
- priate a
40. Gaston
- plantati
41. Robert
- and oca
42. Bellare
- and un
43. Moss
44. Cohen
- Alcoa
45. Master
- aged, i
46. Haube
- http://
47. Fox R

ANNO

1. Coun
- cator
- Over
2. Com
- ing ci
- Revie
3. Cohe
- Alco
- Moss
- Two
4. Deln
- J Me
- Argu
- orga
5. Sche
- Pass
6. Ada
- guid
- Ove

tation cannot
a liver trans-
-up care after
tions, such as

resources in a
allowing our-
while ...
and morally

ness to active
ree resources.
plantation.

in procurement.

? How can it be

plantation: assess-
my Press, 1999.
1991;87:72-77.
tion. *Ann Intern*

rgans from non-

ington: National

skins University

weric organ pro-

ancet 1998;351:

1-1443.

ancet 1998;352:

169):1645-1648.

Polit Policy Law

lantation: results

tical reappraisal.

nsplant 1997;11:

3):904-905.

ults—too much,

kidney in India.

safety and effec-

:1773-1778.

A 2000;284(22):

rations and prac-

d. Chicago: Uni-

i other social fac-

27. UNOS. The UNOS statement of principles and objectives of equitable organ allocation. *Semin Anesth* 1995;14:142-166.
28. Council on Ethical and Judicial Affairs of the American Medical Association. Ethical considerations in the allocation of organs and other scarce medical resources among patients. *Arch Intern Med* 1995;155:29-40.
29. Evans RW, Manninen DL, Dong FB, et al. Heart transplantation recipient and donor selection criteria: the results of a consensus survey. In: Evans RW, Manninen DL, Dong FB, eds. *The national cooperative transplantation study: final report*. Seattle: Battelle-Seattle Research Center, 1991:31-1-31-24.
30. Evans RW, Manninen DL, Dong FB, et al. Kidney transplantation recipient and donor selection criteria: the results of a consensus survey. In: Evans RW, Manninen DL, Dong FB, eds. *The national cooperative transplantation study: final report*. Seattle: Battelle-Seattle Research Center, 1991:30-1-30-24.
31. Evans RW, Manninen DL, Dong FB, et al. Liver transplantation recipient and donor selection criteria: the results of a consensus survey. In: Evans RW, Manninen DL, Dong FB, eds. *The national cooperative transplantation study: final report*. Seattle: Battelle-Seattle Research Center, 1991:32-1-32-24.
32. Sanfilippo FP, Vaughn WK, Peters TG, et al. Factors affecting the waiting time of cadaveric kidney transplant candidates in the United States. *JAMA* 1992;267:247-252.
33. Hauptmann PK, O'Connor KJ. Procurement and allocation of solid organs for transplantation. *N Engl J Med* 1997;336:422-431.
34. Trotter JF, Osgood MJ. MELD scores of liver transplant recipients according to size of waiting list: impact of organ allocation and patient outcomes. *JAMA* 2004;291(15):1871-1874.
35. Evans RW. Organ transplantation costs, insurance coverage, and reimbursement. In: Terasaki PI, ed. *Clinical transplants 1990*. Los Angeles: UCLA Tissue Typing Laboratory, 1990:343-352.
36. Ubel PA, Arnold RM, Caplan AL. Rationing failure: the ethical lessons of the retransplantation of scarce organs. *JAMA* 1993;270:2469-2474.
37. Fox RC, Swazey JP. *Spare parts*. New York: Oxford University Press, 1992:204-205.
38. Young CJ, Gaston RS. Renal transplantation in black Americans. *N Engl J Med* 2000;343(21):1545-1552.
39. Epstein AM, Ayanian JZ, Keogh JH, et al. Racial disparities in access to renal transplantation—clinically appropriate or due to underuse or overuse? *N Engl J Med* 2000;343(21):1537-1544, 2 p preceding 1537.
40. Gaston RS, Danovitch GM, Adams PL, et al. The report of a national conference on the wait list for kidney transplantation. *Am J Transplant* 2003;3(7):775-785.
41. Roberts JP, Wolfe RA, Bragg-Gresham JL, et al. Effect of changing the priority for HLA matching on the rates and outcomes of kidney transplantation in minority groups. *N Engl J Med* 2004;350(6):545-551.
42. Bellamy CO, DiMartini AM, Ruppert K, et al. Liver transplantation for alcoholic cirrhosis: long term follow-up and impact of disease recurrence. *Transplantation* 2001;72(4):619-626.
43. Moss AH, Siegler M. Should alcoholics compete equally for liver transplantation? *JAMA* 1991;265:1295-1298.
44. Cohen C, Benjamin M. The Ethics and Social Impact Committee of the Transplant and Health Policy Center. Alcoholics and liver transplantation. *JAMA* 1991;265:1299-1301.
45. Masterton G. Psychosocial factors in selection for liver transplantation. Need to be explicitly assessed and managed. *Br Med J* 2000;320(7230):263-264.
46. Hauboldt RH, Ortner NJ. 2002 Organ Tissue and Transplant Costs and Discussion. Available at: <http://www.transplantliving.org/beforethetransplant/finance/costs.aspx>. Accessed June 29, 2004.
47. Fox RC, Swazey JP. *Spare parts*. New York: Oxford University Press, 1992:208-209.

ANNOTATED BIBLIOGRAPHY

1. Council on Ethical and Judicial Affairs of the American Medical Association. Ethical considerations in the allocation of organs and other scarce medical resources among patients. *Arch Intern Med* 1995;155:29-40. Overview of the topic.
2. Committee on Organ Procurement and Transplantation Policy. *Organ procurement and transplantation: assessing current policies and the potential impact of the HHS final rule*. Washington: National Academy Press, 1999. Review of proposed federal regulations to improve allocation of scarce organs (particularly livers) for transplantation.
3. Cohen C, Benjamin M. The Ethics and Social Impact Committee of the Transplant and Health Policy Center. Alcoholics and liver transplantation. *JAMA* 1991;265:1299-1301. Moss AH, Siegler M. Should alcoholics compete equally for liver transplantation? *JAMA* 1991;265:1295-1298. Two articles that argue for and against liver transplants in alcoholics, respectively.
4. Delmonico FL, Arnold R, Scheper-Hughes N, et al. Ethical incentives—not payment—for organ donation. *N Engl J Med* 2002;346:2002-2005. Argues that modest financial incentives to reward organ donation are ethically defensible, whereas payment for organs is not.
5. Scheper-Hughes N. Keeping an eye on the global traffic in human organs. *Lancet* 2003;361:1645-1648. Passionate criticism of payments and black markets for organs for transplantation.
6. Adams PL, Cohen DJ, Danovitch GM. The nondirected live-kidney donor: ethical considerations and practice guidelines: A National Conference Report. *Transplantation* 2002;74:582-589. Overview of kidney transplantation from live donors.

Testing for Genetic Conditions

The Human Genome Project, which completed DNA sequencing of all human chromosomes in 2002, has the ultimate goal of developing tests and therapies for illnesses that have a genetic component. Genomics refers to the DNA sequence of chromosomes; genetics refers simply to the science of inheritance. For some genetic diseases, such as sickle cell anemia, phenylketonuria, and Tay-Sachs disease, screening tests have been available for years. DNA-based testing has recently become available for conditions such as cystic fibrosis (CF), familial colon and breast cancer, hemochromatosis, and polycystic kidney disease.

DNA testing for predisposition to adult-onset genetic diseases must be distinguished from carrier screening and prenatal testing. In adult-onset conditions, DNA screening might lead to further diagnostic and therapeutic interventions for the person who is tested. In contrast, carrier screening for recessive conditions has no therapeutic implications for the persons tested but might affect their future reproductive decisions. Prenatal genetic testing raises additional ethical controversies over procreation and abortion.

With ongoing advances in genomics, physicians in all specialties will increasingly be asked to advise patients about genetic testing. This chapter discusses DNA-based screening tests' clinical limitations, genetic discrimination, informed consent for genetic testing, and confidentiality of test results.

WHAT IS DIFFERENT ABOUT GENOMICS?

Although genetic or genomic information is commonly viewed as qualitatively different from other clinical information, on closer examination this claim is untenable.

GENES RARELY DETERMINE DISEASE OR BEHAVIOR

The popular press has characterized the human genome as a "blueprint" for life or as a "future diary." These metaphors imply that a person's DNA sequence determines that person's future. Genomic information is often considered to have greater predictive power than other types of medical information. Single-gene mutations that have complete penetrance cause some severe diseases, such as sickle cell anemia or Huntington disease, but most genes have incomplete penetrance or variable expressivity—that is, their presence does not reliably predict the occurrence of disease. Furthermore, most common conditions are polygenic. For example, whether a person develops hypertension and diabetes will likely depend on several genes, as well as on environmental factors such as diet, exercise, and exposure to viral illness. No matter how clearly we understand human genetics, education and environment as well as heredity determine health and illness.

Ideas at
of racial
marriage
(1). In a
ence us
Duri
"blatant
a sexual
sickle c
health i
fueled a
testing i
today te

Critics of
human
genetic
ties, vio
Adva
ally are
to alcohol
power c
that suc

All gen
tives as
informa
steps to

Every c
lytic val
dicts the
high po
outcome
of benef
fied onl
when st
tion for
ness eve
life plan
Thus
positive
are orde
eases fo
not war

THEORIES OF INHERITANCE HAVE BEEN ASSOCIATED WITH CONTROVERSIAL SOCIAL BELIEFS

Ideas about genetic inheritance were used in the late 19th and early 20th centuries to support ideas of racial superiority as well as discriminatory social policies. Eugenic laws were passed forbidding marriage or mandating sterilization of people categorized as feeble-minded, insane, and criminals (1). In addition, miscegenation laws and restrictive immigration policies were enacted (1). The science used to support such discriminatory policies was deeply flawed (1,2).

During the 1970s many states enacted sickle cell anemia screening programs that contained "blatant medical and scientific errors," such as labeling sickle cell anemia an infectious disease or a sexually transmitted disease and confusing sickle cell disease with the trait (3). Persons with sickle cell trait, who have no impairment or increased risk for disease, were denied employment, health insurance, and schooling. In addition, targeting of these programs at African Americans fueled accusations of genocide (4). Because of this adverse historical legacy, genetic research and testing might be viewed with suspicion or concern. Some people fear that genetics might be used today to justify discriminatory social policies (5).

GENETIC ADVANCES MIGHT UNDERMINE TRADITIONAL MORAL BELIEFS

Critics fear that advances in genetic science might contradict moral and religious teachings about human nature and undermine human dignity (6). For example, some oppose preimplantation genetic diagnosis as fostering a desire for the "perfect" baby, disrespecting persons with disabilities, violating the natural order, and undermining the awe of procreation (6).

Advances in genetics might also change beliefs about individual responsibility. People generally are not considered responsible for inherited conditions. Identification of genes that predispose to alcoholism or drug addiction might weaken the idea that persons with these conditions lack will power or are irresponsible. Instead, evidence of genetic predisposition might strengthen the view that such persons are patients who need medical treatment.

GENETICS PROVIDES INFORMATION ABOUT RELATIVES AS WELL AS THE PROBAND

All genetic information, whether a family history or a DNA test, provides information about relatives as well as the patient. Ethical dilemmas might arise about the confidentiality of genomic information if the proband refuses to share information that would enable relatives to take effective steps to prevent or treat a serious disease.

WHEN IS DNA-BASED GENETIC TESTING APPROPRIATE?

Every clinical test should meet several criteria in order to be adopted in clinical practice (7). Analytic validity means that the test is reliable and accurate. Clinical validity means that the test predicts the presence or absence of clinical disease or condition. In technical terms, the test must have high positive and negative predictive value. Clinical utility means that testing must lead to better outcomes for the patient. The potential benefits of testing must outweigh the risks, and the balance of benefits to risks must be acceptable to the patient. For most conditions a screening test is justified only if there is an intervention that will prevent the disease or if treatment is more effective when started early in the disease (8). Earlier diagnosis alone is not usually considered a justification for screening for risk factors. However, some patients might desire screening for a serious illness even when there is no prevention or treatment because, if positive, they would change their life plans.

Thus, genomic screening tests are most justified if the disease is serious, the test has very high positive and predictive value, and prevention or treatment is effective. However, many DNA tests are ordered in situations that do not meet these criteria (9). The following examples illustrate diseases for which DNA-based genetic tests are appropriate, as well as conditions for which testing is not warranted, even though testing for a specific mutation is technically feasible.

HEREDITARY NONPOLYPOSIS COLORECTAL CANCER (HNPCC)

This autosomal dominant syndrome is caused by mutations in mismatch-repair genes. The most common mutations, MLH1 and MSH2, occur in 2.7% of cases of newly diagnosed colorectal cancer (10). In persons with these mutations, the lifetime risk of colorectal cancer is as high as 85% (11). Also, cancers are more likely to be earlier-onset and synchronous. Screening colonoscopy, which should start around age 20 to 25, has been shown to cut the risk of colorectal cancer in half and decrease overall mortality by 65% (10). In addition to MLH1 and MSH2, many other mutations can cause this syndrome. Hence, testing for only these two mutations has a sensitivity of only 65% and false-negative tests are common.

BRCA1 AND BRCA2

These autosomal dominant genes for susceptibility to breast cancer account for about 2% to 3% of cases of breast cancer. In families with a high incidence of breast and ovarian cancer, mutations in BRCA1 are associated with up to an 85% lifetime risk of developing breast cancer and a 40% risk of ovarian cancer (12).

BRCA testing has important limitations. False-negative tests might occur if a specific mutation has not been identified in an index case in the family. This lack of sensitivity occurs if the test used did not detect a BRCA mutation or if a different gene caused the pattern of illness in the family. The test's limitations are due in part to the patent holder's licensing restrictions, which have discouraged other laboratories from developing tests that screen for additional mutations (13). Another limitation is uncertainty over optimal care for women who are found to have BRCA mutations. Screening mammography should begin earlier for affected women, but the currently available preventive measures, prophylactic mastectomy and oophorectomy, are major interventions that carry significant medical and psychosocial ramifications.

HEMOCHROMATOSIS

Hemochromatosis is a syndrome of cirrhosis, diabetes, and gonadal failure due to iron overload. About one in 200 persons of Northern European descent is homozygous for the mutation C282Y. The value of DNA screening is unproven because of low penetrance even among heterozygotes for this mutation and variable expressivity of disease.

FACTOR V LEIDEN

This abnormal clotting factor, which occurs in 5% of Northern Europeans, confers an increased risk of venous thromboembolism. In women taking oral contraceptives, there is a 30-fold increase in relative risk. However, population screening is controversial because the absolute risk is very low.

GENOMIC TESTING IN CHILDREN

Testing children for increased risk for adult-onset diseases raises concerns because children bear the risk of stigma and discrimination but cannot give informed consent. Such testing is best deferred to adulthood whenever possible. However, testing in childhood might be justified in exceptional cases in which treatment or prevention would lead to a clinically significant benefit for the child.

GENETIC DISCRIMINATION

Screening for genetic disorders might lead to stigmatization and discrimination. Asymptomatic persons at increased risk for adult-onset genetic conditions might regard themselves, or be regarded by others, as impaired, unwhole, or flawed despite their good health. Persons with asymptomatic genetic abnormalities have been reported to suffer discrimination in employment or health insurance (14–16). Furthermore, the belief that it is “irresponsible and immoral for people who could transmit disability to their offspring to reproduce (3)” might cause severe stigma. Because of past abuses in the United States, fears of discrimination resulting from genetic testing need to be taken seriously.

Testing

INSURANCE

In the case of genetic testing, insurance companies would seek to use the results for future underwriting. While some courts have prohibited such use, many others have not. Wide exclusion of people with certain genetic conditions from health insurance is more prevalent in some states than in others.

EMPLOYMENT

Employers might use genetic testing to screen for people who might be more susceptible to certain diseases. Genetic testing might also be used to screen for people who might be more susceptible to certain diseases. Several states have laws that prohibit such testing.

ANTIDISCRIMINATION

The Americans with Disabilities Act (ADA) prohibits discrimination against people with disabilities. Under the ADA, employers are prohibited from asking about a person's genetic information. The ADA also prohibits employers from asking about a person's genetic information.

INFORMATION

Careful attention to the risks of genetic testing is essential. Disclosure of genetic information can have significant psychosocial consequences. If people are not properly informed, they may make decisions that are not in their best interests.

IMPORTANCE

Informed consent is a key principle of medical ethics. It requires that people be given the information they need to make decisions about their health care.

genes. The most
colorectal can-
as high as 85%
ng colonoscopy,
al cancer in half
any other muta-
nsitivity of only

out 2% to 3% of
er, mutations in
r and a 40% risk

pecific mutation
s if the test used
ss in the family.
which have dis-
mutations (13).
ve BRCA muta-
currently avail-
or interventions

to iron overload.
mutation C282Y.
heterozygotes for

an increased risk
d increase in rel-
is very low.

children bear the
best deferred to
exceptional cases
the child.

l. Asymptomatic
emselves, or be
h. Persons with
employment or
moral for people
e severe stigma.
n genetic testing

INSURERS

In the current U.S. health care system, health and life insurance companies have incentives to use genetic testing to avoid adverse selection. Patients who learn that they are at risk for genetic diseases naturally want to be well insured. If insurers cannot identify such high-risk persons, they would sell increased coverage at relatively low rates to people who know they are at increased risk for future illness. Insurers therefore want to know any pertinent medical information that the applicant knows. Companies often refuse to insure people at increased risk for diseases, exclude the diseases from coverage, or set prohibitive premiums. In response to such concerns, most states have prohibited genetic discrimination in health insurance (17).

Widespread genetic testing might be incompatible with the current system of risk rating and exclusion of high-risk persons from coverage (18). With increases in genetic screening, more and more people will be found to be at risk for some genetic disease. If all such persons were in effect excluded from coverage, the very purpose of health insurance—to pay for health care when illness strikes—would be negated.

EMPLOYERS

Employers also have incentives to utilize genetic screening. Excluding employees who are likely to become sick will increase future productivity and cut health insurance premiums. Employers might also want to identify workers at genetic risk for occupational diseases because it might be cheaper to exclude them from the workplace than to reduce occupational exposure.

Genetic testing, however, could be a tragedy for employees identified as at risk for adult-onset conditions (19). They might be unable to find employment, even if they are asymptomatic and able to work productively. In turn, they would be unable to obtain employment-linked health insurance. Several states have enacted legislation banning employment discrimination on the basis of genetic information (17,19).

ANTIDISCRIMINATION LAW

The Americans with Disabilities Act (ADA) bans discrimination against persons who have conditions that result in significant impairment or who are regarded as having a significant impairment. Under the ADA preemployment medical inquiries and examinations are prohibited until after a job offer has been made. Results may not be used to exclude an applicant from the job unless the "exclusion is shown to be job related, consistent with business necessity, and not amenable to reasonable accommodation (20)." In regulations to implement the ADA, the Equal Employment Opportunity Commission (EEOC) has stated that the ADA covers persons who have suffered discrimination based on genetic information—for example, because of a genetic predisposition to a disease (16). The EEOC advisory interpretation does not cover carriers of recessive or sex-linked genetic diseases (18). However, the courts have not adjudicated this issue, and the Supreme Court has narrowed the protections provided under the ADA.

INFORMED CONSENT

Careful attention to informed consent can maximize genetic testing's benefits while minimizing the risks. DNA-based genetic testing differs from most other blood tests because it has significant psychosocial risks (21). Breaches of confidentiality might cause stigma and discrimination. Even if they are asymptomatic, persons found to be at risk for adult-onset illness might regard themselves as abnormal or be regarded as such by family members, teachers, or employers. In addition, patients might experience psychological distress after learning either positive or negative test results; generally the distress is mild, however (22).

IMPORTANCE OF INFORMED CONSENT

Informed consent is particularly important for genetic testing because persons differ on whether the benefits of testing outweigh the risks. Some persons at risk will want more prognostic information, even if its significance is uncertain and no proven preventive or therapeutic intervention is

available. Others will decline testing because they do not perceive themselves to be vulnerable or are concerned about losing health insurance (23).

Truly informed consent for genetic testing will thus be difficult. Genetic concepts and probability are difficult to comprehend. Misunderstandings about genetic testing and the interpretation of results are widespread among health professionals and laypeople alike (9). The availability of multiplex testing, which allows the detection of several genetic conditions from a single blood sample, will further complicate consent.

NONDIRECTIVE GENETIC COUNSELING

Nondirectiveness has been a core tenet in genetic counseling, but people interpret the term differently. It commonly means that all sides of an issue are presented without bias, that the counselor's personal views should not influence the client's decision, and that the client's or couple's decision is respected (24). Historically, the ideology of nondirectiveness developed as a reaction to eugenicist policies and from the desire to distance prenatal genetic diagnosis from controversies over abortion (25).

Empirical studies question whether genetic counselors are in fact nondirective (26). In one study 28% of genetic counselors said they would recommend testing or screening to a client (24). Another study found that genetic counselors gave advice an average of almost six times per session and that clients did not object (27). Fewer than 20% of clients thought they were definitely being steered in a particular direction. Other writers suggest that most problems with nondirectiveness could be solved through better communication skills (28). Counselors can respond to clients' direct questions about what to do by expressing empathy and suggesting issues to consider in making the decision rather than by giving a direct recommendation. Moreover, advice can be framed tentatively as a suggestion rather than as a directive.

The stance of nondirectiveness is ethically problematic for several reasons. First, when patients request advice it might be incompatible with a caring doctor-patient relationship. Second, it might violate ethical guideline of beneficence. Outside the prenatal context, physicians recommend highly predictive screening tests for serious illness for which effective preventive measures or early treatment are available. Finally, the physicians have some obligation to be directive if patients make a decision that is ethically troubling (25). Physicians should encourage patients to share genetic test results with relatives who might be at high risk for a serious disease, and in some situations they might have an obligation to override confidentiality.

RECOMMENDATIONS

Because of the shortage of formally trained genetic counselors (29), physicians will need to help patients make decisions about genetic testing. They need to learn enough about genetic tests to provide sound information and advice.

Provide Pretest Education

To the extent that a DNA-based genetic test is not just another blood test, education about the limitations of testing and psychosocial risks is desirable before testing is carried out. Such pretest education is particularly appropriate for predictive tests that have questionable clinical validity and utility and for conditions that have no effective prevention or treatment.

Make a Recommendation for Testing

Physicians should make a recommendation for genetic testing for susceptibility to adult-onset diseases, just as they would for other screening tests. Both evidence-based medicine and the patient's values and situation should guide these recommendations. In some situations genetic tests are highly predictive of future disease and effective prevention or early treatment is available. Doctors should recommend such tests. In other situations genetic testing will provide little or no guidance for clinical decisions. Physicians should recommend against such testing. Some patients might still want nonrecommended testing (30); their informed choices should be respected.

CONFI

Genetic
DNA-ba
tion. Per
duty to :
autosom
spouse v
patient c

WHEN

The guid
be appli
cancer i:
harm to
sive mea
much gr
allows n
ing colo
situation
tiality. In
person n
he or sh

Some
guished
Howeve
harm to
dentialit
cooperat

Only
late cou
whether
simply f

In m
unjustifi
(32). In
confider
at risk o

RECON

Discuss

Discussi
most dil

Urge Di

Physicia
mation i
Physicia
cerns. F
willing t

Disclosi

In some
tives ove

CONFIDENTIALITY

Genetic testing provides information about relatives as well as about the person being tested. DNA-based genetic testing might have more predictive power than other types of genetic information. Persons identified as having a predisposition to an adult-onset genetic illness have a moral duty to inform relatives who might also be at risk. Similarly, persons identified as carriers of an autosomal recessive condition have a moral duty to disclose such information to their partner or spouse when making reproductive decisions. An ethical dilemma can arise for physicians when the patient objects to such disclosure.

WHEN IS OVERRIDING CONFIDENTIALITY JUSTIFIED?

The guidelines in Chapter 5 for determining whether an exception to confidentiality is justified can be applied to genetic testing. Suppose a colon cancer patient with a strong family history of colon cancer is found to have a mutation for HNPCC but refuses to inform her relatives. The potential harm to identifiable third parties is serious and the likelihood of harm is high. There is no less invasive means for warning relatives at risk because the presence of an MLH1 or MSH2 mutation has much greater predictive power than simply the family history of cancer. Breaching confidentiality allows relatives at risk to take effective steps to prevent harm—namely, initiation of annual screening colonoscopy at an earlier age. Thus there are good reasons to override confidentiality in this situation (31,32). On the other hand, the proband might feel wronged by the breach of confidentiality. In genetic testing the proband's identity can usually be inferred. Another problem is that the person notified might feel that his or her privacy has been violated or might not want to know that he or she is at risk (33).

Some have argued that overriding confidentiality to prevent infectious disease can be distinguished from this case because the person with a genetic condition does not cause the risk (34). However, the rationale behind overriding confidentiality is the prevention of serious and likely harm to unknowing third parties, regardless of the risk's cause. As in most cases in which confidentiality is overridden, it is impossible to identify and contact those at risk if the proband does not cooperate.

Only two cases involving overriding confidentiality of genetic information have reached appellate courts, and the rulings differ on whether the physician has a duty to warn relatives at risk and whether the physician may rely on the proband to warn relatives (35,36). Thus, physicians cannot simply follow the law but need to rely on their ethical judgment.

In most cases of genetic predisposition to adult-onset conditions, overriding confidentiality is unjustified because the test's predictive power is low or there are no effective preventive measures (32). In autosomal recessive conditions such as CF, there are no compelling reasons to override confidentiality. Relatives who might be carriers are at no risk for illness, and their offspring will be at risk only if their partners are also carriers.

RECOMMENDATIONS

Discuss Disclosure during Pretest Counseling

Discussing the importance of disclosure during informed consent process for testing can prevent most dilemmas about disclosure to relatives and spouses.

Urge Disclosure of Positive Results to Relatives or Spouses

Physicians should urge patients to disclose positive results to relatives or spouses when the information is pertinent to their health. In this situation nondirective counseling is highly problematic. Physicians can elicit patients' concerns about sharing test results and help them resolve those concerns. For example, patients who do not want to have contact with estranged relatives might be willing to have the physician contact them.

Disclosure Against the Patient's Wishes Should Be a Last Resort

In some situations there might be compelling reasons to disclose results of genetic testing to relatives over the patient's objections. Such disclosure should be done only as a last resort after attempts

have failed to persuade the patient to allow notification and after the physician has told the patient that notification will occur and has given the patient the option to notify relatives directly. Furthermore, if the person at risk should be offered the information; if he or she has indicated that he/she does not want to know the information, these wishes should be respected.

In summary, physicians will increasingly be asked to help patients weigh genetic testing's benefits and risks. Physicians have an obligation to learn about the new applications of molecular genetics to clinical medicine. In advising patients about genetic testing, physicians need to be aware of testing's clinical limitations, the risk of discrimination, the importance of informed consent, and the need for confidentiality. Physicians as well as society as a whole can take steps to maximize genetic testing's benefits and promise while minimizing the harms.

REFERENCES

1. Kevles DJ. *In the name of eugenics*. Berkeley: University of California Press, 1985:96–112.
2. Gould SJ. *The mismeasure of man*. New York: W.W. Norton & Company, 1981.
3. U.S. Congress Office of Technology Assessment. *Cystic fibrosis and DNA tests: implications of carrier screening*. Washington: U.S. Government Printing Office, 1992:128–129.
4. Stoto MA, Almario DA, McCormick MC. *Reducing the odds: preventing perinatal transmission of HIV in the United States*. Washington: National Academy Press, 1999:28.
5. Nuffield Council on Bioethics. *Genetics and human behavior: the ethical context*. London: Nuffield Council, 2002.
6. President's Council on Bioethics. *Beyond therapy: biotechnology and the pursuit of happiness*. Washington: President's Council on Bioethics, 2003.
7. Secretary's Advisory Committee on Genetic Testing. *Enhancing the Oversight of Genetic Tests: Recommendations of the SACGT*. Available at: <http://www4.od.nih.gov/oba/sacgt/gtdocuments.html>. Accessed April 8, 2004.
8. U.S. Preventive Services Task Force. *Guide to clinical preventive services*. Baltimore: Williams & Wilkins, 1989.
9. Giardiello FM, Brensinger JD, Petersen GM, et al. The use and interpretation of commercial APC gene testing for familial adenomatous polyposis. *N Engl J Med* 1997;336:823–827.
10. Lynch HT, de la Chapelle A. Hereditary colorectal cancer. *N Engl J Med* 2003;348(10):919–932.
11. Calvert PM, Frucht H. The genetics of colorectal cancer. *Ann Intern Med* 2002;137(7):603–612.
12. Wooster R, Weber BL. Breast and ovarian cancer. *N Engl J Med* 2003;348(23):2339–2347.
13. Cho MK, Illangasekare S, Weaver MA, et al. Effects of patents and licenses on the provision of clinical genetic testing services. *J Mol Diagn* 2003;5(1):3–8.
14. Hudson KL, Rothenberg KH, Andrews LB, et al. Genetic discrimination and health insurance: an urgent need for reform. *Science* 1995;270:391–393.
15. Lapham EV, Kozma C, Weiss JO. Genetic discrimination: perspectives of consumers. *Science* 1996;274:621–624.
16. Miller PS. Genetic discrimination in the workplace. *J Law Med Ethics* 1998;26:189–197.
17. Clayton EW. Ethical, legal, and social implications of genomic medicine. *N Engl J Med* 2003;349(6):562–569.
18. Rothstein MA. Genetic privacy and confidentiality: why it's so hard to protect. *J Law Med Ethics* 1998;26:198–204.
19. Rothenberg K, Fuller B, Rothstein M, et al. Genetic information and the workplace: legislative approaches and policy changes. *Science* 1997;275:1755–1757.
20. Americans with Disabilities Act of 1990. 42 USC §§12181, 12182.
21. Grady C. Ethics and genetic testing. *Adv Intern Med* 1999;44:389–411.
22. Marteau TM, Croyle RT. Psychological responses to genetic testing. *Br Med J* 1998;316:693–696.
23. Lerman C, Narod S, Schulman K, et al. BRCA1 testing in families with hereditary breast-ovarian cancer. *JAMA* 1996;275:1885–1892.
24. Bartels DM, LeRoy BS, McCarthy P, et al. Nondirectiveness in genetic counseling: a survey of practitioners. *Am J Med Genet* 1997;72:172–179.
25. Caplan AL. Neutrality is not morality: the ethics of genetic counseling. In: Bartels DM, LeRoy BS, Caplan AL, eds. *Prescribing our future: ethical challenges in genetic counseling*. New York: Aldine De Gruyter, 1993:149–165.
26. Williams C, Alderson P, Farsides B. Is nondirectiveness possible within the context of antenatal screening and testing? *Soc Sci Med* 2002;54(3):339–347.
27. Michie S, Bron F, Bobrow M, et al. Nondirectiveness in genetic counseling: an empirical study. *Am J Hum Genet* 1997;60:40–47.
28. Kessler S. Psychological aspects of genetic counseling: nondirectiveness revisited. *Am J Med Genet* 1997;72:164–171.
29. Andrews LB, Fullerton JE, Holtzman NA, et al., eds. *Assessing genetic risks: implications for health and social policy*. Washington: National Academy Press, 1994.
30. Benkendorf JL, Reutenauer JE, Hughes CA, et al. Patients' attitudes about autonomy and confidentiality in genetic testing for breast-ovarian cancer susceptibility. *Am J Med Genet* 1997;73(3):296–303.
31. Andrews LB, Fullerton JE, Holtzman NA, et al., eds. *Assessing genetic risks: implications for health and social policy*. Washington: National Academy Press, 1994.
32. The American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure. Professional disclosure of familial genetic information. *Am J Hum Genet* 1998;62:474–483.
33. Wickel JTR. Late onset genetic disease: where ignorance is bliss, is it folly to inform relatives? *Br Med J* 1998;317:744–747.

34. Sulmasy DP. On warning families about genetic risk: the ghost of Tarasoff. *Am J Med* 2000;109:738-739.
35. Safer v. Pack. 677 A.2d 1118 (N.J. App.).
36. Pate v. Threlkel. 662 So.2d 278 (Fla. 1995).

ANNOTATED BIBLIOGRAPHY

1. Marteau TM, Croyle RT. Psychological responses to genetic testing. *Br Med J* 1998;316:693-696.
Comprehensive review of patient responses to genetic testing.
2. Rothstein MA. Genetic privacy and confidentiality: why it's so hard to protect. *J Law Med Ethics* 1998;26:198-204.
Thoughtful discussion of problems with measures to prohibit genetic discrimination within the current U.S. insurance system.
3. Rothenberg K, Fuller B, Rothstein M. Genetic information and the workplace: legislative approaches and policy changes. *Science* 1997;275:1755-1757.
Analyzes recent policy developments regarding workplace discrimination based on genetic information.
4. The American Society of Human Genetics Social Issues Subcommittee on Familial Disclosure. Professional disclosure of familial genetic information. *Am J Hum Genet* 1998;62:474-483.
Position paper on whether genetic information should be disclosed to relatives over the objections of the patient.
5. Offit K, Groegner E, Turner S, Wadsworth EA, Weiser MA. The "duty to warn" a patient's family members about hereditary disease risks. *JAMA* 2004;292:1469-1473.
Analyzes the dilemma of whether to inform relatives at risk for late-onset genetic diseases.
6. Clayton EW. Ethical, legal, and social implications of genomic medicine. *N Engl J Med* 2003;349(6):562-569.
Recent comprehensive review of the topic.

Ethical Issues in Public Health Emergencies

In 2001 the attacks on the World Trade Center and the Pentagon and the subsequent outbreaks of inhalational anthrax raised concerns about bioterrorism. The federal government developed a vaccination strategy in case of a smallpox outbreak initiated by terrorists. In 2003 severe acute respiratory syndrome (SARS) rapidly spread to many countries through international travel. These incidents dramatize how serious public health emergencies might require large-scale public-health interventions. Measures such as quarantine, isolation, and compulsory vaccination raise public policy dilemmas about how to protect the public health while still respecting individual freedom and treating different groups equitably (1–5).

This chapter focuses on the clinical dilemmas that physicians will confront because some patients will disagree with public health measures. Some will not accept restrictions on their freedom of movement and others will want preventive measures that are not recommended.

RECENT PUBLIC HEALTH EMERGENCIES

In October 2001 cases of inhalational anthrax occurred in several states. In Washington, D.C., congressional staff who were exposed to anthrax contained in a letter were offered prophylactic antibiotics within hours. In contrast, prophylactic antibiotics for postal workers were delayed, even after several workers were hospitalized with what was determined to be anthrax pneumonia. Concerns were raised that working class, predominately African-American postal workers received less timely prophylactic care than predominately Caucasian congressional staff. Across the country, during the season of upper respiratory infections and influenza, many people presented to emergency departments and physician offices with concerns about inhalational anthrax. Prescriptions for ciprofloxacin, the recommended drug for inhalational anthrax, increased so much that a shortage of this antibiotic was feared. The anthrax outbreaks illustrate how knowledge about an outbreak is incomplete and evolving, how perceptions of discrimination might arise, and how people might request preventive measures beyond those recommended by public health officials.

In 2002 the Centers for Disease Control and Prevention (CDC) developed plans for smallpox vaccination of first responders to an outbreak. At first the union for emergency medical technicians (EMTs) pressed for vaccination of the families of EMTs, arguing that they could be exposed to smallpox through clothing worn by EMTs (6). However, wider vaccination before an outbreak was rejected because the vaccine was in limited supply and because of risks to immunosuppressed third parties. Ironically, vaccination of first responders later fell far short of target levels because of the risk of cardiac adverse events. The smallpox vaccination program illustrates how preventive interventions might need to be triaged and how persons might demand greater access to such measures than public health guidelines recommend.

The SARS epidemic in 2002–2003 illustrated how emerging infections might spread rapidly from country to country in the era of international airplane travel. Public health responses varied markedly in different nations (7,8). In China officials locked patients and health care workers in hospitals that experienced many cases of SARS. In Canada, in contrast, exposed persons were quarantined in their homes.

HOW ARE ETHICAL ISSUES IN PUBLIC HEALTH DIFFERENT?

FOCUS ON THE PUBLIC GOOD RATHER THAN ON THE INDIVIDUAL PATIENT

Public health focuses on assessing benefit and risk to the public rather than to the individual patient (1,9). It might be appropriate for public health officials to impose compulsory public health measures to respond to a serious, probable threat to the public. Such measures might restrict freedom of movement, as through quarantine or isolation. In addition, mandatory interventions may be imposed, such as testing, treatment, and vaccination. Thus, the autonomy and liberty of individual patients may be overridden in an emergency for the public good. This is a sharp difference from ordinary clinical practice, in which individual patients decide whether to accept or decline an intervention based on their own assessment of the benefits and risks of the intervention.

INDIVIDUAL AUTONOMY MIGHT BE OVERRIDDEN

Public officials must observe ethical guidelines when imposing mandatory interventions in response to a serious and probable harm to the public health (1,3,4,9). The intervention should be effective in addressing the threat and be the least restrictive alternative that will do so. There should be procedural due process for persons deprived of their freedom and autonomy. That is, persons who are subjected to compulsory measures should have the right to an open, impartial, and timely appeal of their case. Furthermore, the benefits and burdens of the public health interventions should be equitably distributed across society, consistent with the threat's epidemiologic features. In the past, public health measures were sometimes applied discriminatorily and persons and groups affected by epidemics were often stigmatized (5,10). However, no group should bear an unjust share of the burdens of public health interventions or gain an unjust share of the benefits. Even the perception that some groups are being treated unfairly will undermine public support for compulsory measures.

Public health policies in an emergency fall within the authority of public health officials, not individual clinicians. Physicians should presume that public measures are reasonable and fair if they are developed through appropriate decision-making procedures. If doctors have questions or disagreements, they should raise them with officials rather than take it on themselves to override guidelines. Public health officials generally welcome such input from frontline physicians.

Ultimately, public health officials have police powers to enforce public health mandates. However, mandatory measures have costs and adverse effects that need to be taken into account. Isolation and quarantine raise difficult social, financial, and logistic challenges (11). Public health investigations, particularly in unprecedented outbreaks, usually require affected persons' cooperation, and the use of force might undermine such cooperation. Hence, public health officials generally invoke compulsory measures only as a last resort after less drastic measures have failed to control an outbreak. It is not necessary to have 100% enforcement of isolation or quarantine in order to stem an outbreak (11).

WEAKER EVIDENCE BASE

The evidence base for interventions in public health emergencies might be weaker than the evidence base for clinical practice. Knowledge about new conditions such as SARS or inhalational anthrax is incomplete and develops over time. Accurate diagnostic tests might not be available at the start of an outbreak. For fatal or serious conditions, there can be no definitive clinical trials of new vaccines or therapies because it would be unethical to administer the infectious agent to volunteers. Moreover, public health officials might need to act quickly on the basis of uncertain and incomplete information.

PATIENT DISAGREEMENTS WITH PUBLIC HEALTH POLICIES

In public health emergencies physicians in clinical practice will encounter patients who believe that infringements on their autonomy are unwarranted or unfair. Two different scenarios might arise: Patients might request interventions beyond those recommended or patients might refuse public health measures.

REQUESTS FOR INTERVENTIONS NOT RECOMMENDED IN PUBLIC HEALTH GUIDELINES

CASE 43.1 Patient who requests antibiotics.

During the anthrax outbreaks in the fall of 2001, a 48-year-old man requests a prescription for ciprofloxacin. He is a Federal Express driver who has had no exposure to anthrax but is concerned that he is at high risk for exposure in light of the cases of anthrax transmitted through the mail. "Look at what happened to those postal workers in Washington. Two of them died, and there were delays in getting them antibiotics. If I see white powder, I want to take the antibiotics right away." After the physician explains that there are concerns about a national shortage of the antibiotic of choice if a massive outbreak occurs, the patient retorts, "That's ridiculous. Look at those office workers in Congress who weren't even exposed. They got cipro in a few hours. They weren't told there was a shortage."

In ordinary clinical practice, when patients request interventions that are not indicated, physicians generally attempt to persuade the patient (see Chapter 32). Nevertheless, physicians often accede to such requests as long as the intervention does not present undue risk to the patient. In contrast, in a public health emergency it might not be appropriate or feasible to provide requested interventions that fall outside the guidelines (12).

Protect the Public Health

In public health emergencies physicians have a primary obligation to act for the common good. Unlike in ordinary clinical practice, physicians need to consider how a decision for one patient might significantly affect the spread of an epidemic, public trust, and perceptions of fairness. If many patients receive nonrecommended interventions, the press is likely to report the story. In turn, people might believe that the guidelines are being unfairly implemented or that the magnitude of the threat is greater than officials acknowledge. As a result, trust in public health officials might be undermined.

A particular case might be a justified exception to public health policies or might show that a policy needs to be modified. The burden of proof in an emergency is on those who argue that an exception or modification is warranted. An exception must be fair in the sense that it would also apply to all patients in a similar clinical situation, not just in that particular case. If such a widespread exception would not be feasible from a public health perspective, it is difficult to justify making an exception for an individual patient.

Physicians should clarify how strictly public health guidelines are to be enforced; officials might accept less than full compliance. In Case 43.1 it might be plausible to write a prescription for ciprofloxacin for someone in a high-risk occupation. Guidelines in this context reflect recommendations, as opposed to mandatory rules. In other situations, however, public health interventions are tightly controlled and the physician might have little or no discretion. For instance, early in the smallpox vaccination program, explicit criteria for eligibility were set because of a shortage of vaccine.

Physicians should help patients understand that in a public health emergency decisions need to be based on public health considerations as well as their personal preferences. The impact on the well-being of other persons and the public is paramount. Although resource constraints exist in ordinary clinical care (see Chapter 30), they usually are not the determining factor in decisions.

Act in the Patient's Best Interests

In so far as it is possible, physicians should maintain their usual role of acting in the patient's best interests while observing public health guidelines that are strictly enforced.

Eli
natura
physic
Trying
more

Us
epider
their c
warni

Ad
and ne
limite
also b
contro

REFU

CASE

During
Five da
not ne
comm
health
objects
over th

In c
respec
Comple
break

Prote

Physic
some s
ing inf
tals or
quaran
cian m

Act in

Ad
with p
who hi
reporte
sound
great e

Est.
physic
familie
if they
with p
availat

Elicit and address patient concerns and emotions. Fear and a sense of loss of control are natural human reactions to public health emergencies and they need to be acknowledged. Also, physicians should acknowledge the uncertainty inherent in a situation where knowledge is evolving. Trying to reassure people by telling them not to worry is unlikely to be effective. Patients might be more willing to pay attention to public health after their own needs are addressed.

Use the doctor-patient relationship to benefit patients. As was demonstrated in the SARS epidemic, patients can often be reassured if they believe they can see the physician promptly if their condition worsens or fails to improve (13). Also, patients can be reassured by knowing what warning signs they should watch for.

Address patient concerns in other ways. It might be possible to address the patient's concerns and needs without affecting public health. For example, if access to ciprofloxacin were strictly limited, the physician could prescribe antibiotics that are not in such short supply and that might also be effective. When patients have a prescription and access to follow-up care, their sense of control might be increased to the extent that they decide not to take the drug.

REFUSAL OF PUBLIC HEALTH INTERVENTIONS

CASE 43.2 Patient who rejects quarantine.

During the SARS epidemic in 2002, a 48-year-old businessman presents with fever, cough, and malaise. Five days before, he returned from a trip to a country where SARS cases have been reported but he was not near the area in which the cases occurred. He says his symptoms are no different from what he commonly experiences after such long travel. Because SARS cases have been reported in his city, public health officials are requiring physicians to report such cases for consideration of home quarantine. He objects strongly. "If I had known that, I wouldn't have come in. I have a lot of meetings that I can't do over the phone. My business would go down the tubes if I were in home quarantine."

In clinical practice when patients refuse recommended interventions, their informed wishes are respected. However, in public health emergencies, individual autonomy is not paramount (1). Compulsory measures may be imposed to prevent transmission to others and to control an outbreak of a serious infection.

Protect the Public Health

Physicians need to be clear about the limits of their discretion in public health emergencies. In some situations doctors might have little control over public health measures. Reporting of emerging infections or infections related to bioterrorism might be mandatory and done directly by hospitals or clinical laboratories rather than by individual physicians. In other situations isolation and quarantine might be voluntary rather than mandatory; if this is the situation in Case 43.2, the physician may exercise discretion.

Act in the Patient's Best Interests (12)

Advocate for changes in guidelines or exceptions. Doctors should communicate disagreement with public health guidelines to responsible officials. For example, a policy of quarantine for all persons who have traveled to a particular country might not be warranted if cases of the disease have been reported only from a well-defined area of a large country. Justifications for exceptions need to have a sound public health basis. It would be ethically inappropriate to argue that patients who would suffer great economic losses should be exempted from home quarantine.

Establish common ground with the patients. When patients refuse public health measures, physicians can still find areas of agreement. For example, most patients do not want to infect their families. Also, business people might suffer greater harm to reputation and business relationships if they flout public health measures and others are infected as a result. Furthermore, cooperating with public health officials might enable patients to have access to special tests that are not otherwise available.

Mitigate the risks of mandatory public health interventions. Physicians can assuage the adverse psychosocial consequences of quarantine or isolation by keeping in telephone contact with patients and addressing their feelings of isolation. In addition, physicians can help address practical concerns—for example, by referring patients for social services and for legal assistance as needed.

Refrain from Deception

Patients might ask doctors to intentionally misrepresent their condition in order to exempt them from public health policies. For instance, patients might ask physicians to certify that they do not have a reportable condition. Such deception to third parties is ethically problematic for physicians (see Chapter 6). If doctors intentionally mislead third parties who have an ethical and legal right to information about the patient, they cannot be trusted to tell the truth in other situations. Moreover, the harms of such deception outweigh the benefits when the adverse consequences to other patients and the public are taken into account.

In summary, in public health emergencies time for physicians to deliberate about a particular case might be limited. Further public health emergencies are to be expected. Before a crisis occurs, physicians should think through in advance how they would respond to foreseeable dilemmas that arise when patients disagree with public health recommendations or requirements.

REFERENCES

1. Childress JF, Faden RR, Gaare RD, et al. Public health ethics: mapping the terrain. *J Law Med Ethics* 2002;30(2):170–178.
2. Gostin LO. When terrorism threatens health: how far are limitations on human rights justified. *J Law Med Ethics* 2003;31(4):524–528.
3. Gostin LO. Public health law in an age of terrorism: rethinking individual rights and common goods. *Health Aff (Millwood)* 2002;21(6):79–93.
4. Gostin LO, Sapsin JW, Teret SP, et al. The Model State Emergency Health Powers Act: planning for and response to bioterrorism and naturally occurring infectious diseases. *JAMA* 2002;288(5):622–628.
5. Gostin LO, Bayer R, Fairchild AL. Ethical and legal challenges posed by severe acute respiratory syndrome: implications for the control of severe infectious disease threats. *JAMA* 2003;290(24):3229–3237.
6. Board on Health Promotion and Disease Prevention, ed. *Scientific and Policy Considerations in Developing Smallpox Vaccination Options: A Workshop Report*. Washington, D.C.: National Academies Press; 2002.
7. Institute for Bioethics Health Policy and Law. Quarantine and Isolation: Lessons Learned from SARS. May 13, 2004. Available at: <http://mmr.fda.gov/News/SarsWatch/2004/may/nsars2004-05-13.aspx>. Accessed July 18, 2004.
8. Knobler S, Mahmoud A, Lemon S et al., eds. *Learning from SARS: Preparing for the Next Disease Outbreak*. Washington, D.C.: National Academies Press; 2004.
9. Gostin LO. *Public Health Law: Power, Duty, Restraint*. Berkeley: University of California Press; 2000.
10. Person B, Sy F, Holton K, Govert B, et al., NICD/SARS Emergency Outreach Team. Fear and stigma: the epidemic within the SARS outbreak. Available at: <http://www.cdc.gov/ncidod/EID/vol10no2/03-0750.htm>.
11. Centers for Disease Control and Prevention. Community Containment Measures, Including Non-Hospital Isolation and Quarantine. Jan 8, 2004. Available at: <http://www.cdc.gov/ncidod/sars/guidance/D/index.htm>. Accessed July 18, 2004.
12. Lo B, Katz MH. Clinical decision-making during public health emergencies: ethical considerations. In press.
13. Maunder R, Hunter J, Vincent L, et al. The immediate psychological and occupational impact of the 2003 SARS outbreak in a teaching hospital. *Cmaj* 2003;168(10):1245–1251.

ANNOTATED BIBLIOGRAPHY

1. Childress JF, Faden RR, Gaare RD, et al. Public health ethics: mapping the terrain. *J Law Med Ethics* 2002;30:170–178.
Presents ethical framework for public health policies.
2. Gostin LO, Sapsin JW, Teret SP, et al. The Model State Emergency Health Powers Act: planning for and response to bioterrorism and naturally occurring infectious diseases. *JAMA* 2002;288:622–628.
Proposes model state legislation to grant emergency powers to public health officials while still respecting individual liberties.
3. Lo B, Katz MH. Clinical decision-making during public health emergencies: ethical considerations. Under review.
Analyzes ethical dilemmas that frontline clinicians face during public health emergencies.

INFORM

CASE 1

An asym-
cific anti-
a Gleason
Suppose

QUESTIONS

1. You
cans
patie
rathe
purp
2. An in
the p
I am
every
3. Supp
gery
your
4. One
physi
don't
dent's
5. A stu
gery
about
care
consi

REFUS

CASE 2

A 64-yea
drainage
sis. Howe
and over
weight lo
another e
shows no

QUESTIONS

1. The p
arrest.
arrest
Resus
2. What
ration.

ialties

ge the
ct with
ddress
istance

it them
do not
sicians
right to
reover,
patients

rticular
occurs,
nas that

ics 2002;

'ed Ethics

Health Aff

g for and

ndrome:

veloping

12.

r 13, 2004.

2004.

Outbreak.

1.

a: the epi-

al.

pital Isola-

Accessed

press.

003 SARS

Med Ethics

response to

ecting indi-

nder review.

Cases for Discussion

INFORMED CONSENT

CASE 1. Choosing among therapeutic options for prostate cancer.

An asymptomatic 52-year-old teacher is diagnosed with prostate cancer on the basis of a prostate-specific antigen of 5.4 (normal < 4.0) and a needle biopsy that shows several foci of adenocarcinoma with a Gleason score of 3 + 3 = 6. Options for treatment include surgery, radiation, or "watchful waiting." Suppose that you are the attending surgeon.

QUESTIONS FOR DISCUSSION

1. You are hosting a visiting physician from China, who says he does not understand why Americans regard informed consent as so important: "I can understand that in your country, you tell patients they have cancer. But why don't you then just do what is the best treatment for them rather than going through what you call informed consent?" How would you explain (a) the purposes of informed consent and (b) the ethical reasons for informed consent?
2. An intern asks you how to determine what information about surgery he needs to discuss with the patient. "I just read a chapter in a surgery textbook, and I'm not sure how much information I am supposed to tell him to get informed consent," he says. "There's no way I can tell him everything! What do I need to discuss with him?" How would you answer the intern's question?
3. Suppose, on the basis of your critical reading of the published evidence, you believe that surgery offers the best outcome for this patient. How do you take into account this judgment in your discussions with the patient?
4. One resident has read articles reporting that patients don't understand basic information that physicians discuss with them and says, "Why do we bother with the informed consent? Patients don't understand what we say and don't remember any of it." How do you respond to the resident's objections?
5. A student asks if patients need to be told of the role that students and residents play during surgery and in postoperative care. One of the residents says, "We don't need to tell the patient about that. They have given implied consent to have residents and students participate in their care by choosing to come to a teaching hospital." Do you agree or disagree? Give the ethical considerations for your position. How have the courts used the term "implied consent"?

REFUSAL OF CARE

CASE 2. Refusal of treatment by a patient with inoperable cancer.

A 64-year-old man has inoperable pancreatic cancer and obstructive jaundice. He had an internal drainage tube placed in the common duct in an attempt to decompress his biliary tree and prevent sepsis. However, he developed cholangitis, which was treated with antibiotics. He entered hospice care, and over the next 2 weeks he had progressive jaundice, abdominal pain, nausea, pruritis, anorexia, and weight loss. His life expectancy is a few weeks. His drainage tube obstructs and he is admitted with another episode of biliary sepsis. As his physician, you discuss with him plans for care. He is lucid and shows no sign of mental impairment during your conversation.

QUESTIONS FOR DISCUSSION

1. The patient says he does not want cardiopulmonary resuscitation (CPR) if he suffers a cardiac arrest. In a number of studies, no patients with metastatic cancer who suffer a cardiopulmonary arrest leave the hospital alive after attempted resuscitation. Would you write a Do Not Attempt Resuscitation (DNAR) order? How would you explain your decision?
2. What would you do if his wife or family disagrees with his refusal of CPR? What is the ethical rationale for your decision?

3. The patient also refuses antibiotics for biliary sepsis, saying: "There isn't any point in going through this again only to have another infection next week or the week after." The intern exclaims, "How can we not give him antibiotics? He'll die without them, and we have an ethical duty to save lives." Do you agree to withhold antibiotics? What is the ethical rationale for your position?

CASE 3. Refusal of blood transfusions by a Jehovah's Witness.

A 34-year-old man is hospitalized after an automobile accident that ruptures his spleen. A devout Jehovah's Witness, he refuses transfusion. He does agree to a splenectomy and states emphatically, "I wish to live, but with no blood transfusions." He also refuses blood components and court-ordered transfusions. He declares, "It is between me and Jehovah, not the courts. I'm willing to take my chances. My faith is that strong." He is lucid throughout the conversation.

QUESTIONS FOR DISCUSSION

1. His hematocrit drops to 14.1%. One of the residents says, "How can we just stand by when we could bring him back to full health with transfusions? Aren't doctors supposed to act for the good of the patient? How can it be good for a young, healthy man to die needlessly?" Do you agree with the resident? What is the ethical rationale for your position?
2. The patient's wife was a Jehovah's Witness but left the faith. "I know that he says he doesn't want a blood transfusion, but I also know he loves his children," she says. "He could never agree to a transfusion, but he couldn't bear to leave us either. Can't you override his decision? That's what he would really want you to do." How do you respond to the wife? Explain the ethical rationale for your approach.
3. The surgeon is reluctant to operate without transfusion support. "What's the point of taking someone to the operating room to have him die on the table?" he says. "If he wants to refuse transfusions and die in the emergency room, that's his right. But he can't force me to operate and be responsible for his death." Do you agree or disagree with the surgeon? What is the ethical rationale for your position?

CASE 4. No clear reason for refusal of medically effective treatment.

A 45-year-old woman has a 1/2-cm breast mass that is found to be malignant on needle aspiration. With either mastectomy or lumpectomy plus radiation, she has an excellent chance of being cured of her cancer. She refuses any form of therapy, saying that she wants to try natural healing through herbal remedies, megavitamin therapy, spiritual healing, and relaxation techniques.

QUESTIONS FOR DISCUSSION

1. One resident objects, "How do we just stand by when she would most likely be cured of her cancer with surgery? Aren't we supposed to act in the patient's best interests? How can it be in the patient's best interests to lose the chance to have her cancer cured?" Another resident says, "Wait a minute, we're supposed to respect patient autonomy. It's her body and her life, and it's her decision." How do you respond to these viewpoints? What is the ethical rationale for your position? How would you carry out your position in practice?

CONFIDENTIALITY

CASE 5. Reporting a patient with syncope to the Department of Motor Vehicles.

A 76-year-old retired teacher with a history of coronary artery disease is hospitalized after a syncopal episode. He is found to have ventricular tachycardia. He had two previous syncopal episodes during the past 3 years. An automatic implantable cardioverter defibrillator (AICD) is implanted. During the first year after implantation, about 10% of patients experience syncope or near-syncope because of defibrillation.

QUESTIONS FOR DISCUSSION

1. A nurse in a clinic asks if the patient needs to be reported to the Department of Motor Vehicles. How do you respond? What ethical considerations support your position?

2. Suppose that your patient is a 47-year-old bus driver instead of a retiree. The patient tells you that he is willing to try anything, even take temporary leave from work, as long as you don't report him to the Department of Motor Vehicles. "Doc, if you take my license away, I can't support my family," he pleads. "I need this job." How do you respond? What ethical considerations support your position?

CASE 6. Use of anabolic steroids by an athlete.

A colleague asks your advice on a difficult case. A 19-year-old college swimmer reveals that she has started to take oral anabolic steroids, which she obtains through friends at the gym where she lifts weights. She says that she is aware of the long-term side effects but plans to use the drugs only while she is competing in intercollegiate athletics. She doesn't want to lose her scholarship; because many of her competitors are using steroids, there is no other way for her to be competitive.

QUESTIONS FOR DISCUSSION

1. Your colleague asks whether she should tell the coach of the swim team about the patient's steroid use, saying, "Maybe she can discourage her from taking these drugs. It's so dangerous for her, and her health can't be worth winning a few races. We need to act in her best interests." How do you respond? What ethical considerations support your position?
2. Another colleague, who joins your discussion, suggests: "She should be reported to the intercollegiate athletic officials. It isn't fair to swimmers at other schools for her to have an advantage. If she wants to risk her health, that's her business, but let's keep the playing field level." How would you respond? What ethical considerations support your position?
3. A third colleague says, "If you tell anyone, it should be her parents. If I were her mother, I'd certainly want to know." What is your view on talking to her parents? What ethical considerations support your position?

CASE 7. Disclosure of genetic illness to relatives

A 40-year-old auto mechanic is found to have a localized breast cancer, which is treated with lumpectomy and radiation. Because of a family history of both ovarian and breast cancer in several first-degree relatives, she is tested for BRCA-1 and is found to be positive for a mutation that is known to confer a greatly increased risk for these cancers. As her physician, you discuss the implications of this autosomal recessive condition for her 34-year-old and 36-year-old sisters and urge her to disclose her test results to them so they also can be tested for BRCA1. A relative who has the same mutation has a lifetime 85% risk of breast cancer and a 50% risk of ovarian cancer. An affected relative will probably want to begin screening mammography earlier than is usually recommended and also want to consider interventions such as bilateral mastectomy, tamoxifen, and experimental therapies. Your patient refuses to disclose her results to her sisters or allow you to do so. "We had a major falling out when mom died," she tells you. "They did some things that I'm not sure I can ever forgive. I just don't want to get involved with them at this point in my life."

QUESTIONS FOR DISCUSSION

1. A nurse is outraged at the patient's refusal to inform her sisters that they might be at high risk for cancer. "We should pick up the phone and call them," she says. "This is more serious than tuberculosis and we notify contacts of TB patients. What if her sisters get tested later and have inoperable cancer?" How do you respond to the nurse? What ethical considerations support your position?

DECISION-MAKING CAPACITY**CASE 8. Refusal of colonoscopy.**

A 72-year-old retired lawyer comes into the hospital with lower abdominal pain. He is found to have guaiac positive stools and anemia. You plan to do a colonoscopy, but the patient refuses. During your conversation, you learn that the patient spends all day closed inside his house where the electricity has been turned off due to outstanding bills.

One intern says that it is appropriate to seek a court order, saying, "This guy can't even pay his bills, how can we expect him to make decisions about his health care?" Another intern responds, "Look, I have trouble paying my bills on time. I hope that no court would override my medical decisions."

The patient's only relative is a niece who lives in a distant state. She says that he is somewhat cantankerous and has always been independent and stubborn. She is unable to persuade him over the phone to have the colonoscopy. She tells the doctors, "If you believe that he's not able to make decisions for himself, I would certainly give permission for you to the tests and treatments he needs. I want the best care for him."

QUESTIONS FOR DISCUSSION

1. What will happen if it is determined that the patient is competent to make medical decisions? If he is determined to lack decision-making capacity?
2. What questions would you ask the patient to better evaluate whether he is competent to make decisions about his care?
3. The intern says, "I was told that we have to get a psychiatry consultation to declare a patient incompetent." Do you agree or disagree? What ethical considerations support your position?

DECISIONS FOR INCOMPETENT PATIENTS

CASE 9. Mechanical ventilation in end-stage lung disease.

A 72-year-old retired grocery store owner with end-stage interstitial lung disease presents to the Emergency Department (ED) for shortness of breath that began 4 hours ago. On room air, she is breathing at a rate of 36, is cyanotic, and has an O_2 saturation of 54%. She is afebrile and has no signs of consolidation. Her chest x-ray shows no infiltrates. She pulls nasal canulae or mask delivering oxygen off her face. Her daughter is unable to get her to keep the supplemental O_2 on. The patient is unable to have a coherent conversation. At baseline her FEV1 is 0.8 liters and her room air blood gas is PH 7.38, pO_2 51 mm Hg, PCO_2 55 mm Hg.

QUESTIONS FOR DISCUSSION

1. The daughter says that her mother knows that she has end-stage lung disease and has told her ambulatory physician several times that she does not want to be intubated. The patient has also told the daughter that she would not want intubation. Her daughter reports, "She knows what intubation is. She had it several years ago when she had pneumonia. But she knows that her lungs have just gotten worse and worse. She's ready to die when the time comes, but she wants to die with dignity, without machines or tubes." However, she has never completed a durable power of attorney for health care, and there is no Do Not Intubate/Do (DNI) order in the computerized record system. You are unable to get the ambulatory records, and the on-call physician does not know the patient. Your resident says doctors must provide treatment for potentially reversible conditions, saying, "This is probably an aspiration pneumonia, from which she could recover. Without a written advance directive or DNI order, we have to intubate her." Do you agree? What are the ethical justifications for your position?
2. One intern says, "We have to intubate her. All we know is what the daughter is telling us. How can we be sure that she is accurately reporting what her mother wants? You never can trust family members; maybe she is trying to get an inheritance. Whenever there is any doubt, we have to err on the side of preserving life." The other intern responds, "But that means we would never trust any family to make decisions for an incompetent patient, except when patients complete a health care proxy. That doesn't seem right." Do you agree with the first intern? What are the ethical justifications for your position? How might the intern's concerns be addressed in emergency situation?

CASE 10. Stroke and aspiration pneumonia.

A 74-year-old retired gas station owner with Alzheimer disease and coronary artery disease is admitted with a stroke. Three days after admission he has a dense hemiplegia, is unable to speak coherently, and has difficulty swallowing. An ECG also shows an acute myocardial infarction with many premature

ventricular contractions. He develops an aspiration pneumonia that is treated with antibiotics. At his baseline he often does recognize family members and needs help with all activities of daily living. He has not given any written advance directives.

QUESTIONS FOR DISCUSSION

1. His wife and daughter report that he had said many times that becoming demented and living in a nursing home would be a fate worse than death. He had helped care for an uncle with Alzheimer disease and had said that not being able to recognize people and take care of himself would be intolerable. The wife and daughter request that he be transferred out of the intensive care unit (ICU) and allowed to die. They want a Do Not Attempt Resuscitation (DNAR) order, no intubation, no feeding tube, and no antibiotics for infections. "Just keep him comfortable and let him die in peace," they say. They report that in the emergency room they agreed to active treatments because they were told that his stroke might be reversible and that he might return home. However, he has not improved after 3 days. They are unable to care for him at home because of his wife's medical problems and his daughter's job. They also cannot afford to hire full-time help. The nurses comment that they seem devoted to him.
2. How would the ethical analysis be different if the patient had completed an advance directive appointing his wife as proxy?

CASE 11. Stroke and aspiration pneumonia.

Assume the same medical facts as in Case 3, but the patient has made no statements about his preferences for care. His wife and daughter believe that he would not want to receive continued ICU care after failing to improve from his stroke. "He never really talked about what he would want in this situation for himself," his wife explains. "But he was a man who prided himself on his independence and dignity. He never wanted anyone to help him when he was injured or sick. He was always immaculately dressed. He would never even go out to pick up the newspaper in the morning before getting dressed because he didn't want anyone to see him in his robe or pajamas. It's hard enough for him to have us help him. He would be mortified to have strangers help him with his bathing and dressing. We've been married over 50 years, and I know in my heart he wouldn't want to live like this."

QUESTIONS FOR DISCUSSION

1. The intern says that without some indication of the patient's own preferences, either written or oral, it is inappropriate to discontinue antibiotics or write a DNAR-DNI order. "What the wife is saying is pure speculation," the intern points out. "He may still improve from his stroke." Do you agree with the intern? What are the ethical justifications for your position?

CASE 12. Stroke and aspiration pneumonia.

Assume the same medical facts as in Case 3, but the patient has made no statements about his preferences for care and has no family members. He has lived in a nursing home for several years and has no friends who visit him regularly. The nurses did not know him before he became demented.

QUESTIONS FOR DISCUSSION

1. One of the interns says, "We have to continue ICU care because we don't know what the patient would want in this situation. Without any surrogate, we have to give maximal treatment. How can we say that it's better for him to be dead than to live like this, when we don't know him?" Do you agree with the intern? What are the ethical justifications for your position?

CONFUSING ETHICAL DISTINCTIONS

CASE 13. Withdrawal of mechanical ventilation.

A 72-year-old retired grocery store owner with end-stage interstitial lung disease was intubated in the ED. Later you obtain old records, which document extensive discussions with her primary physician that

she does not want to be intubated or have resuscitation attempted. You also speak with the primary physician, who confirms that the patient did not want to be intubated and says, "This is exactly what she most feared—that she be on a ventilator with nothing readily reversible."

QUESTIONS FOR DISCUSSION

1. An ICU nurse says, "I would have no problem if we hadn't intubated her in the first place. But we can't just turn off the ventilator or extubate her. She would die in a couple of minutes. That would be killing her, pure and simple, just as if we injected potassium." Do you agree with the nurse? What are the ethical justifications for your position?
2. Because the patient will be dyspneic, you want to administer morphine and also provide sedation. An intern objects, saying that it could reduce her respirations or lower her blood pressure, which would kill her: "That would be active euthanasia, and that's wrong." Do you agree? What are the ethical justifications for your position?

DO NOT ATTEMPT RESUSCITATION ORDERS

CASE 14. Do Not Attempt Resuscitation orders during endoscopy.

A 58-year-old woman with dysphagia is found to have inoperable carcinoma of the esophagus. She realizes her poor prognosis and opts for palliation. With the concurrence of her family, she agrees to a DNAR and DNI order. Because she has difficulty maintaining adequate oral intake, she agrees to endoscopic placement of an intraluminal esophageal stent.

QUESTIONS FOR DISCUSSION

1. The gastroenterologist who performs the procedure insists that the DNAR order be lifted during the procedure, saying, "I understand that she has chosen palliative care. However, if she has a cardiac arrest during the endoscopy, it is due to the medications that we give for conscious sedation. Our ability to resuscitate patients in this situation, even those with inoperable cancer, is close to 100%. The situation is completely different from a cardiopulmonary arrest that occurs spontaneously in the course of illness." Do you agree with the gastroenterologist that the DNAR order should be suspended during the procedure? What are the ethical justifications for your position?

CASE 15. Pneumonia and Alzheimer disease.

A 74-year-old man with severe Alzheimer disease is transferred from a nursing home for treatment of pneumonia. Except for mild hypercholesterolemia and osteoarthritis of the knees and hips, he has no active medical problems and takes no medications regularly. He has no living relatives or friends, and before becoming demented he had not indicated what he would want done in such a situation. His baseline state in the nursing home is that he requires assistance with all activities of daily living, including eating. He usually does not recognize nursing home staff, but he does smile when watching television. The nursing home physician says that he does not know what the patient would want but that it seems reasonable to administer antibiotics but not to provide interventions such as mechanical ventilation.

QUESTIONS FOR DISCUSSION

1. The resident on the team says, "He should be DNAR. It doesn't make any sense to resuscitate someone with such a terrible quality of life. It would be futile." Do you agree with the resident's view? What are the ethical justifications for your position?

FUTILE INTERVENTIONS

CASE 16. Multiorgan failure.

Mr. D is a 72-year-old homebound man with multisystem failure admitted to a community hospital for pneumonia, a myeloproliferative disorder, and failure to thrive. He develops stupor and adult respiratory

distress syndrome (ARDS), for which he requires mechanical ventilation. He is transferred to a referral center, where he develops renal failure requiring dialysis and recurrent episodes of hypotension and sepsis. No primary site of infection has been identified.

His major problem now is abdominal pain and distention, which requires fentanyl. A CT scan shows dilated extrahepatic bile ducts but no intrahepatic dilatation or other abnormalities. His liver function tests are only mildly and occasionally elevated. The patient's daughter believes that an operation on his biliary tract would cure his abdominal problem and that relief of his abdominal distention would in turn allow him to be weaned off the ventilator. Surgery believes that there is no abdominal problem that surgery would improve and that general anesthesia would be lethal. Two attempts at endoscopic retrograde cholangio-pancreatography (ERCP) were unable to visualize the ampulla of Vater. Interventional radiology is unwilling to attempt percutaneous biliary drainage because there is no intrahepatic duct dilatation.

The patient has given no advance directives. The patient's wife tends to defer to the daughter in discussions and agrees with her. His family believes that if he had widespread cancer or were in a permanent coma he would not want life-prolonging treatment, but they point out that this is not currently the case. They refuse to agree to a DNAR order or limitation of medical interventions.

QUESTIONS FOR DISCUSSION

1. The surgical chief resident says that it would be "crazy" to operate on this patient and remarks, "There is no reason to operate. It would be futile. We won't take her to the Operation Room, no matter what the family wants." Do you believe that exploratory laparotomy would be futile and that the surgery team may refuse to do the procedure? What are the ethical justifications for your position?
2. The gastrointestinal (GI) service declines to make another attempt at ERCP. The GI fellow says, "We've already tried the procedure twice. There's no point in trying again. The family can't force us to do something that's futile." Do you believe that ERCP would be futile and that the GI team may refuse to do the procedure? What are the ethical justifications for your position?
3. The nephrology service believes that continuing dialysis is futile, saying, "What's the point of dialyzing him? That's not going to allow him to leave the ICU." Do you believe that continued dialysis would be futile and that the nephrology team may refuse to do the procedure? What are the ethical justifications for your position?
4. The resident believes that CPR would be futile and says, "If he has a cardiac arrest, there's no way he would survive. We don't need the family's agreement to withhold CPR. We can write a medical DNAR order." You try to find evidence to support the claim that CPR would be futile in this situation. Do you believe that CPR would be futile and that the medical team may write a DNAR order against the wishes of the family? What are the ethical justifications for your position?
5. When you sign out the patient to the night float resident, she notes that the last time she covered, the patient suffered an episode of hypotension, which she treated with fluids, vasopressors, and antibiotics. "What if that happens again, but he doesn't respond and develops progressive hypotension despite maximal therapy?" she asks. "Do you still want me to do CPR if he suffers a cardiac arrest?" In that situation would it be appropriate to withhold CPR despite the family's wishes? What are the ethical justifications for your position?

PHYSICIAN-ASSISTED SUICIDE AND ACTIVE EUTHANASIA

CASE 17. Head and neck cancer.

A 57-year-old machinist has head and neck cancer that has progressed despite radiation and chemotherapy. She cannot swallow foods and secretions and has to sit upright at night to spit out her secretions. She asks her physician for a prescription for a lethal dose of sleeping pills and says, "It's barbaric that the medical system does not allow me to retain the last shreds of my dignity. Why can't I have the same humane, compassionate treatment that we give our pets at the end of their

lives? I do not want to wait for pneumonia or starvation to deliver me. I want to end my life freely and rationally. I am not depressed, but it is inhumane to ask me to live this way." Her husband agrees with her decision.

QUESTIONS FOR DISCUSSION

1. What actions should a physician who supports physician-assisted suicide take before deciding that it is appropriate to write a prescription for a lethal dose of medication in this case?
2. What actions should a physician who opposes physician-assisted suicide take in addition to refusing the patient's request?
3. How does the moral responsibility of the physician differ when writing a lethal prescription compared to injecting a lethal dose of medication, such as potassium?

CASE 18. Failed suicide attempt.

The patient with head and neck cancer is found at home by her husband after a suicide attempt. She has ingested a combination of tricyclic antidepressants, barbiturates, and alcohol and has left a long explanatory suicide note. She had held a good-bye party for her friends and then ingested the medications while he played her favorite music. As they agreed, they left her alone for 3 hours. When he returned with a friend, they were shocked to find her grunting for breath but not conscious. Horrified that she was suffering, they called 911.

In the field she is found to have an O_2 saturation of 70% and is intubated. In the ED she is placed on mechanical ventilation and given intravenous fluids and vasopressors. The patient's primary physician confirms her diagnosis, her recent deterioration, and the absence of depression or other psychiatric illness, saying, "She didn't want to be a burden on her family or spend her last days waiting for an infection. I personally wouldn't do what she did, but I respect her choice. There is no question that she thought about this long and hard."

QUESTIONS FOR DISCUSSION

1. Would you continue mechanical ventilation, fluids, and vasopressors? One ED resident says, "If we withdraw support, we'll be abetting a suicide. That's illegal and morally wrong. What message does it send to other patients if the emergency room helps people kill themselves?" Do you agree with this position? What are the ethical justifications for your position?
2. While the medical and nursing staff are discussing the case, the patient begins to awaken. She is weaned off vasopressors, and 2 hours later she is extubated. As per ED protocol, a psychiatrist talks with her. She says, "Of course, I'll do this again as soon as I get home and can figure out how to do it right. We'll have to get on the Internet and find out. Don't you understand that waiting for some medical catastrophe to occur is an inhumane way to die? Wouldn't you do the same thing? Do you expect me to lie about my intentions to make you all feel less guilty?" As the psychiatrist, do you place her on an involuntary hold because she is actively suicidal? What are the ethical justifications for your position?

CASE 19. Withdrawal of mechanical ventilation.

A 72-year-old retired grocery store owner with end-stage interstitial lung disease has mechanical ventilation withdrawn based on evidence that she would not want such treatment. She is placed on oxygen via nasal canulae and morphine and diazepam drips to palliate her dyspnea and anxiety. On 10 mg morphine per hour and 2 mg diazepam per hour, the patient appears comfortable, without any tachypnea, use of accessory muscles, tachycardia, or restlessness. Her respiratory rate is 12 per minute. She does not respond when called or when an intravenous line is restarted.

QUESTIONS FOR DISCUSSION

1. The patient's family requests that you increase the drips: "She said many times she didn't want to linger or to have a prolonged death." Do you agree with the family's request? What are the ethical justifications for your position?

REFUSAL TO CARE FOR PATIENTS

CASE 20. Caring for a patient with acquired immunodeficiency syndrome.

A 34-year-old man with acquired immunodeficiency syndrome (AIDS) (CD4 level 47) is admitted to your service with *Pneumocystis carinii* pneumonia. His IV has infiltrated, and you are asked to restart it.

QUESTIONS FOR DISCUSSION

1. How would you feel if you suffered a needlestick injury while caring for an HIV-infected patient?
2. One of the interns on the admitting team refuses to take care of this patient. What are the ethical considerations if:
 - a. The intern says he is inexperienced at starting IVs and thinks that a more experienced physician should care for the patient.
 - b. The intern is a deeply religious person who believes that homosexuality is a sin. Because the patient is gay, the intern does not want to care for him.
 - c. The patient is an injection drug user. An injection drug user at the hospital had earlier mugged the intern in his internship. The intern is still experiencing flashbacks about that earlier incident and does not want to be subjected to more stress.

ETHICAL DILEMMAS FACING STUDENTS AND HOUSE STAFF
LEARNING ON PATIENTS**CASE 21. Outcomes of coronary artery bypass and graft.**

Suppose your favorite uncle has been recommended to have coronary artery bypass and graft (CABAG) by his primary care physician and cardiologist in New York. From your clinical epidemiology course you recall that the mortality rates for this operation vary from under 1% to over 8% and that New York State publishes mortality rates for hospitals and for individual surgeons.

QUESTIONS FOR DISCUSSION

1. Do you want to know the outcomes experience for the hospital or for the surgeon who would operate on your uncle? What are your reasons?

CASE 22. Carrying out an invasive procedure.

Recall the first time you did a lumbar puncture (LP) (or central line, major suturing, or other major procedure).

QUESTIONS FOR DISCUSSION

1. How did you feel before doing your first invasive procedure?
2. One of your classmates says that by coming to a teaching hospital, patients have given implied consent to having students and residents do procedures. Thus there is no need to tell the patient that a student will be performing a procedure. Do you agree, and why?
3. What would you do if before your first LP, the resident calls to say go ahead and do it yourself, because he and the interns are in the emergency room with critically ill new patients. The LP needs to be done today. How would you respond?

CASE 23. Unethical behavior of an attending physician.

On a clerkship you observe what you consider flagrantly unethical behavior by one of your attending physicians. On several occasions, his speech is slurred and you smell alcohol on his breath. He also fails to round on his patients for days at a time, without having anyone cover for him, and does not return your pages or those of your resident.

QUESTIONS FOR DISCUSSION

1. What are the ethical reasons for reporting the situation to an appropriate senior physician?
2. What are some of the risks in reporting the situation?
3. In practical terms, how might you proceed?

DISCLOSING ERRORS**CASE 24. Muscle weakness due to inadequate potassium replacement.**

A 42-year-old man is admitted to you with diabetic ketoacidosis. After treatment with intravenous fluids and an insulin drip, the patient's glucose declines from 745 to 289 mg per dl after 4 hours. However, the patient develops progressive leg weakness and difficulty breathing and requires transfer to the ICU for mechanical ventilation. In reviewing the case, you check the computer for labs results and realize that the patient had a potassium of 2.3 mmol per L. No potassium replacement had been given during the treatment of the ketoacidosis.

QUESTIONS FOR DISCUSSION

1. If you were the subintern on the case, what would your feelings be?
2. In your experience, how have colleagues reacted to mistakes?
3. What would your concerns be about telling the attending physician about this mistake?
4. Would you tell the attending physician about the episode?

CASE 24, continued.

The patient's family asks what happened. They say that the patient has been hospitalized several times for ketoacidosis but has never required mechanical ventilation.

QUESTIONS FOR DISCUSSION

1. A nurse asks you what she should tell the patient and family, saying that they are very concerned about what happened. How do you respond? What are the ethical reasons for your response?

ETHICAL ISSUES IN PEDIATRICS**CASE 25. Treating adolescents without parental consent.**

A 15-year-old high-school student comes to the physician because of dysuria and a discharge from his penis after intercourse without a condom. He wants to be tested and treated but does not want his parents to know about his problems. "They would completely freak out if they knew I was having sex," he says.

QUESTIONS FOR DISCUSSION

1. You ask a colleague whether you can treat the patient without his parents' authorization. She says that you may do so, provided that he is capable of giving informed consent to treatment. Do you agree with her advice? What are the ethical justifications for your position?
2. The patient is so concerned about his parents' finding out that he asks you to write on the encounter form that the visit is for shoulder pain. "I don't want them getting a bill that tells them why I came in." How do you respond to this request? Give the ethical considerations for your decision.

CASE 26. Treating children despite refusals.

A 10-year-old boy is taken to the ED with vomiting and right lower quadrant abdominal pain and is found to have appendicitis.

QUES

1. Th
no
Th
he
the
2. Su
ch:
rec
der
the

QUESTIONS FOR DISCUSSION

1. The patient says that he does not want surgery, saying that the pain is getting better and he does not want to have a scar the rest of his life. His parents are willing to authorize surgery for him. The resident on the team says, "We're not going to operate on a patient who is screaming that he doesn't want surgery. That's assaulting the patient." Do you agree with the resident? Give the ethical considerations for your decision.
2. Suppose instead that the parents refuse surgery. (An aunt who was baby-sitting brought the child to the ED.) The parents are devout Christian Scientists who believe that their child will recover with prayer therapy. The intern says that parents are not permitted to make irrational decisions, so the surgery should proceed as recommended. Do you agree with the intern? Give the ethical considerations for your decision.

an?

ious flu-
however,
the ICU
d realize
n during

ral times

ery con-
for your

from his
t his par-
sex," he

ion. She
eatment.

e on the
that tells
tions for

in and is

Subject Index

A

- Abandonment, patient, 161
- Abortion, 252–253
 - providing information about, 251–252
- Abuse
 - child
 - Baby Doe Regulations and, 242
 - reporting, 42–43
 - elder, reporting, 42–43
 - partner, reporting, 42–43
 - possibility of with physician-assisted suicide/active euthanasia, 133
 - possibility of with psychiatric patients, 257–259
 - withholding tube and intravenous feedings and, 126
- Acquired immunodeficiency syndrome (AIDS). *See* HIV infection/AIDS
- Active euthanasia, 130–138, 130, 287–295
 - abuse and, 133
 - administering appropriate doses of narcotics/sedatives differentiated from, 131
 - case study of, 287–295
 - compassion for suffering patient and, 132
 - consequences for survivors, 135
 - de facto legalization of in Netherlands, 135
 - declining request for, 137
 - definition of, 130
 - physician confusion about, 134
 - depression and, 132–133, 136–137
 - improved palliative care affecting patient desire for, 136
 - incidence of requests for, 134
 - involuntary, 130
 - justifiable situations and, 137
 - legal status and practice of, 134
 - nonvoluntary, 130
 - patient autonomy and, 131
 - patient withdrawal of request for, 135
 - physician role as healer and, 133
 - policy options and, 135–36
 - reasons against, 132–33
 - reasons favoring, 131–32
 - requests, 132
 - response to request for, 136–138, 136r
 - safeguard violations and, 135
 - sanctity of life and, 132
 - suffering and relief, 132
 - unintended consequences, 135
 - voluntary, 130
 - withholding/withdrawing medical interventions differentiated from, 131
- ADA. *See* Americans with Disabilities Act
- Adolescent patient, 238–241
 - confidentiality issues and, 240–241
 - parental consent for abortion and, 252–253
 - reproductive health for, 251–252

- Advance directives, 59, 79–86
 - conflict with patient's best interests and, 82
 - discussing with patient
 - documenting, 85
 - improving, 83–86
 - ongoing evaluation in, 85
 - problems with, 83
 - rationale for, 82–84
 - health care proxy/durable power of attorney for health care, 80–82
 - interpretation of, 81–83, 85–86
 - limitations of, 81–83
 - living wills, 81
 - misunderstandings about, 81
 - oral, 79–81
 - physician-assisted suicide/active euthanasia requests and, 134
 - trustworthiness of, 79–81
 - types of, 80–82
 - written, 80–82
- Advocate. *See* Patient advocate
- Affirmative (positive) rights, 100
- Agreement with physician
 - decision-making capacity and, 68
 - informed consent and, 17–18, 20
- AIDS. *See* HIV infection/AIDS
- Alcohol use
 - during pregnancy, 254
 - liver transplantation and, 271
- Allocation of resources, 13, 189. *See also* Bedside rationing
 - of health care
 - cost of transplantation and, 271–272
 - futility of interventions and, 63
 - patient insistence on interventions and, 33
- "Allowing to die," 131
- Alternative approaches
 - informed consent and, 18
 - surgery and, 244–246
- American College of Physicians–Society for Internal Medicine, code of ethics of, 5
- American Medical Association (AMA), code of ethics, 5
- Americans with Disabilities Act (ADA), 277
- Anesthesia, for surgery and invasive procedures,
 - suspension of DNR order and, 122
- Artificial feedings, 125–128. *See also* Intravenous feedings; Tube feedings
- Assisted reproductive technologies, 250–251, 254
- Automobile drivers, impaired, reporting to public officials, 40–41
- Autonomy
 - patient insistence on interventions and, 32
 - physician/caregiver insistence on life-sustaining interventions and, 32
 - potential for in children, 235–236

B

- Baby Doe
- Barbiturate
- Battery, in
- Bedside rationing
 - argume
 - argume
 - financi
 - notifica
 - suggesti
- Beneficence
- patient
- life-s
- transpla
- confi
- Benzodiaz
- Best intere
- acting f
- advance
- bedside
- childrer
- conflict
- deceptiv
- decision
- fiduciar
- futility
- medical
- patient
- patient i
- life-s
- patient
- physicia
- problem
- professi
- promoti
- reaching
- resource
- substitu
- treating
- Birth contr
- Blood tran
- children
- increasi
- refusal
- Bonuses fo
- Brain deatl
- concept
- controve
- definitic
- higher b
- legal sta
- organ tr
- persiste
- practica
- rejection
- whole-b
- Breast canc

Autonomy (*contd.*)

- refusal of treatment and, 75
 - physician/hospital insistence on life-sustaining interventions and, 99
 - respect for persons and, 10–11

B

- Baby Doe Regulations, 242
- Barbiturates, for terminal sedation, 108–09
- Battery, informed consent and, 22
- Bedside rationing of health care, 189–194. *See also* Allocation of resources
 - arguments against, 190
 - arguments supporting, 190–192, 190*r*
 - financial resources as basis for, 192–193
 - notification of patient/surrogate and, 194
 - suggestions for physicians considering, 193–194, 194*r*
- Beneficence, 11, 29–31. *See also* Best interests of patient
 - patient insistence on interventions and, 31–34
 - life-sustaining interventions and, 96–97
 - transplant recipient selection and, 269–270
 - conflicts and, 271
- Benzodiazepines, for terminal sedation, 108–109
- Best interests of patient, 11, 28–34. *See also* Beneficence
 - acting for patient benefit and, 33
 - advance directive conflicting with, 82
 - bedside rationing of health care and, 189–194
 - children and, 235–237
 - conflicts of interest and, 186, 187. *See also* Conflicts of interest
 - deception/nondisclosure and, 49
 - decisions for incapacitated patients and, 12, 87–88
 - fiduciary relationship between doctor and patient and, 29–30
 - futility differentiated from, 64
 - medical paternalism and, 31
 - patient autonomy and, 32
 - patient insistence on interventions and, 31–34.
 - See also* Futile interventions
 - life-sustaining interventions and, 96–97
 - patient refusal of beneficial interventions and, 11, 28–31
 - physician autonomy and, 32
 - problems with, 30–31
 - professionalism and, 29–30
 - promotion of in shared decision making, 24–26, 33–34, 34*r*
 - reaching agreement on, 33–34
 - resource allocation and, 33
 - substituted judgment conflicting with, 87
 - treating patients against their wishes and, 77–78
- Birth control, providing information about, 251–252
- Blood transfusions
 - children and, 241
 - increasing risk of surgery and, 247–249
 - refusal of by Jehovah's Witnesses, 76–77
- Bonuses for reduced expenditures, as cost-containment measure, 205. *See also* Financial incentives
- Brain death
 - concept of, 143–144
 - controversies regarding, 144–145
 - definition of, 143–144
 - higher brain/neocortical definition of, 144–145
 - legal status of, 144–145
 - organ transplantation and, 143, 145, 265
 - persistent vegetative state differentiated from, 141
 - practical suggestions regarding, 145
 - rejection of concept of, 144
 - whole-brain criteria for, 143–144
- Breast cancer susceptibility, DNA-based testing for, 276

C

- Cadaver donors
 - criteria for acceptability of, 265
 - non-heart-beating, harvesting organs from, 267–269
- Capitation, as cost-containment measure, 205.
 - See also* Financial incentives
- Cardiopulmonary criteria, for brain death, 144
- Cardiopulmonary resuscitation (CPR)
 - complications of, 117–118
 - effectiveness of, 117–118
 - discussing with patients, 119–121
 - as futile intervention, 118–119
 - orders to withhold (DNR orders), 117–123
 - patient refusal of, 118
 - physician recommendations about, 120
 - surrogate refusal of, 118
- Care. *See also* Doctor–patient relationship; Health care resources; Health care services; Interventions (treatment)
 - goals of, futility defined in terms of, 63
 - incentives to decrease, 200–206
 - incentives to increase, 196–198
 - obligations to provide, 157–158
 - refusal of, 287
 - refusal to provide, 157–161
 - substandard, disclosing mistakes and, 213–219
- Caregivers. *See also* Health care workers
 - Physician beliefs about withdrawing life-sustaining interventions and, 99
 - risk of acquiring HIV infection and, 158
- Caring
 - ethic of, 15
 - tube and intravenous feedings as symbol of, 127
- Carrier screening, DNA-based testing for adult-onset diseases
 - differentiated from, 274
- Case consultations, 8, 111–116
 - access to/requesting, 114
 - building consensus, 112
 - consultation team, 116
 - ethics committees for, 111
 - ethics consultants for, 111
 - facts clarification, 111
 - goals of, 111–113, 112*r*
 - participants in, 114
 - patient participation, 113
 - problems with, 113–114, 113*r*
 - procedures for, 114
- Casuistry, 14–15
- Cesarean section
 - emergency, consent and, 252
 - forced, 254–255
- CF. *See* Cystic fibrosis
- Child abuse/neglect
 - Baby Doe Regulations and, 242
 - reporting, 42–43
- Childbirth, 250
- Children, 235–242
 - brain death determination in, 144
 - confidentiality and, 239–241
 - decision-making for
 - adolescents and, 238–241
 - disagreements between parents and physicians and, 237–239
 - informed decisions and, 235
 - parents and, 237–238
 - standards for, 237–238
 - disclosure of information to, 239
 - ethical issues in care of, 235–242

- Children (*contd.*)
 handicapped infants and, 242
 interests of parents/family members and, 237
 parental requests for treatment of, 239
 physician as advocate for, 235-237
 potential autonomy and, 235-236
 preferences of, 235-236, 241
 protecting best interests of, 235-236
 refusal of interventions and, 241-242
 relationship of pediatrician to, 239-241
- Citizenship, transplant recipient selection and, 270-271
- Clinical ethics, 3-6. *See also* Decision making,
 ethical; Ethical dilemmas in patient care
 law and, 5-6
 as moral guidance source, 3-5
 professional oaths/codes differentiated from, 5
 theories of, 13
 use of by physicians, 5-7
- Clinical interventions. *See* Interventions
- Clinical protocols, in cost containment, 206
- Clinical research
 misconceptions, 179
- Clinical research ethics, 176-181
 academic rewards and, 180
 competing interests and, 179-181
 confidentiality of data from, 179
 conflicting interests and, 180
 constrained consent and, 177
 drug manufacturer funding and, 180
 finder's fees and, 179
 informed consent and, 177-179, 178t
 Institutional Review Board and, 179
 participant selection and, 177
 patient lacking decision-making capacity and, 177
 research protocols and, 176-177
- Clinical skills, basic, learning on patients, 227
- Clinician-investigators. *See also* Clinical research
 academic rewards for, 180
 dual roles for, 180
- Codes of ethics, clinical ethics and, 5
- Coercion, informed consent and, 20
- Comfort measures. *See also* Pain relief
 for patients refusing tube and intravenous feedings, 127
- Commitment, involuntary. *See* Involuntary
 psychiatric commitment
- Communicable diseases. *See* Infectious diseases
- Communication, improvement of, ethics case
 consultations and, 112. *See also* Discussions
- Competence, 59, 67-73. *See also* Decision-making capacity
 legal standards for, 68-69
 physician-assisted suicide/active euthanasia and, 133
- Competing interests
 clinical research and, 179-181
 conflicting interests differentiated from, 186
- Computerized medical records, confidentiality breaches
 and, 36
- Conception, philosophical/religious questions about, 250
- Conferences, drug companies paying for/sponsoring, 209-210
- Confidentiality, 11, 36-43, 288
 adolescents' requests for, 240-241
 difficulties in maintenance of, 36-38
 disclosure of information and, 38-39
 public figures and, 38
 to relatives and friends, 38-39
 exceptions to/overriding, 37t, 39-43
 child abuse and, 42-43
 domestic violence and, 43
 elder abuse and, 42-43
 genetic testing information and, 278-279
 justifications for, 39-40, 40t
 partner notification and, 41, 42
 patients who are dangerous to others and, 41, 261-263
 to protect patients, 37t, 42
 to protect third parties, 37t, 39-42, 40t
 public health reporting and, 40-41
 warning persons at risk and, 41-42
- Federal Health Privacy Regulations, 37
- genetic testing and, 278-280
- omission of information from medical record and, 38-40
- pediatric issues and, 239
- psychiatric conditions and, 258
 warning persons at risk of harm and, 41, 261-263
- reasons for, 36
- of research data, 179
- value of, 37
- waivers of, 37
- Conflicts of interest
 best interests of patient and, 12
 in clinical research, 180
 competing interests differentiated from, 186
 definition of, 186-187
 disclosure of, 188
 gifts from drug companies and, 209-212
 health care rationing and, 189-194
 incentives to decrease services and, 200-206
 incentives to increase services and, 196-198
 managing, 187-188, 187t
 in nonmedical situations, 185-186
 overview of, 185-188
 perceived, 186-187
 protecting patients and, 188
 reimbursement incentives and, 187, 196, 201-202
 self-referral and, 196-198
 students/house staff and, 226-231
 surrogate decision making affected by, 92-93
- Confusing ethical distinctions, 291
- Conscience, claims of, as justification of action, 4
- Consent
 constrained, for clinical research, 177
 implied, 23
 informed. *See* Informed consent
 presumed, for organ donation, 267
- Consent forms, 22-23
- Consequentialist ethical theories, 13
- Consultations
 ethical, 8, 111-116. *See also* Case consultations
 neurologic, brain death declaration and, 145
- Contact tracing, 41
- Continuing medical education, drug companies paying
 for/sponsoring, 209-210
- Contraception, providing information about, 251-252
- Cost-containment measures, in managed care, 205-206.
See also Health care costs
- Counseling, genetic, nondirective, 277-278
- Court-appointed guardian, as surrogate, 90-91
- CPR. *See* Cardiopulmonary resuscitation (CPR)
- Crimes, injuries involving
 determination of death and, 143
 reporting, 41
- Cultural factors
 in deception/nondisclosure, 46
 insistence on life-sustaining interventions and, 98
- Cystic fibrosis (CF), DNA-based testing for, 274-276

D

- Dead patient, learning procedures on, 228
- Death. *See also* Brain death
 definition/determination of, 143-145

Death (c
 organ
 probl
 victim
 Decepti
 avoid
 ma
 sec
 definit
 nondi
 of pat
 resi
 of thir
 resi
 Decision
 ethical
 app
 are
 clar
 dile
 guik
 ider
 info
 lega
 mor
 prof
 for chi
 adol
 disa

 info
 pare
 stan
 patient.
 unw
 unw
 bi
 in
 shared
 app
 best
 infor
 prom
 reasc
 surroga
 unilater
 abou
 for cl
 justif
 probl
 safeg
 Decision-n
 assessm
 clinic
 clinical
 compre
 delusion
 emergen
 enhanci
 ethical i
 making/
 mental i
 refus
 refus
 patient l
 advan
 best i
 caring

Death (*contd.*)

- organ transplantation and, 143, 145, 265
- problems with cardiopulmonary criteria for, 143
- victims of crime and, 143

Deception

- avoidance of, 11, 45–53
 - managed care systems and, 203–204
 - secret information about patients and, 174–175
- definition of, 45
- nondisclosure, 46–50
- of patient, 46–50
 - resolving dilemmas about, 47–50, 48t
- of third parties, 49–51
 - resolving dilemmas about, 50–53, 53t

Decision making

- ethical
 - approach to, 6–9, 7t
 - areas of consensus and controversy and, 6
 - clarifying issues and, 7–8
 - dilemma resolution and, 8
 - guidelines for, 10–15
 - identification of issues and, 6
 - information gathering and, 7, 7t
 - legal issues and, 5–6
 - moral guidance sources and, 4–5
 - professional oaths and codes and, 5
 - for children
 - adolescents and, 238–241
 - disagreements between parents and pediatricians and, 237–239
 - informed decisions and, 235
 - parental, 237–238
 - standards for, 237–238
 - patient. *See also* Decision-making capacity.
 - unwillingness and, 21
 - unwise/harmful
 - best interests of patient and, 11, 28–34
 - informed consent and, 21, 26
 - shared
 - approach to, 59–60
 - best interests of patient and, 24–26, 33–34, 34t
 - informed consent and, 18, 24–26, 24t
 - promoting, 24–26, 24t
 - reasons for, 18–19
 - surrogate, 90–94. *See also* Surrogate
 - unilateral
 - about cardiopulmonary resuscitation, 118–119
 - for children, 237–239
 - justification of, 61–63
 - problems with, 63–65
 - safeguards and, 64–65, 64t
- Decision-making capacity, 67, 289. *See also* Competence
- assessment of, 70–73
 - clinical context and, 70–71
 - clinical standards for, 68–71, 69t
 - comprehension of information and, 68–71
 - delusions/distorted views of reality and, 70
 - emergencies and, 73
 - enhancing, 72
 - ethical implications of, 68
 - making/expressing choice and, 69
 - mental illness and, 72, 257–259
 - refusal of medical treatment and, 263
 - refusal of psychiatric treatment and, 262–263
 - patient lacking, 59, 79–88, 80t
 - advance directives and, 59, 79–86
 - best interests of patient and, 11–12, 87–88
 - caring for, 73
 - clinical research and, 177
 - informed consent and, 20, 23–24
 - legal issues related to life-sustaining interventions and
 - Cruzan case ruling and, 148–149
 - Quinlan case ruling and, 147–148
 - Schiavo case ruling and, 150–151
 - physician-assisted suicide/active euthanasia and, 133
 - standards for decisions with, 79–88, 80t
 - substituted judgment and, 85–88
 - patient's values and goals and, 69–70
 - reasoning and, 70
 - religious beliefs and, 72–73
 - Delusions, decision-making capacity affected by, 70
 - Dementia, severe, persistent vegetative state
 - differentiated from, 141
 - Deontological ethical theories, 13
 - Depression
 - decision-making capacity and, 72
 - requests for assisted-suicide/active euthanasia and, 133
 - Deselection, as incentive to provide fewer services, 206
 - Diabetes, prenatal testing for, 252
 - Diagnosis
 - discussing bad news and, 51–53
 - withholding. *See* Nondisclosure
 - Disagreements among family members
 - Schiavo case ruling on, 150–151
 - Disclosure. *See also* Nondisclosure
 - benefits of, 47
 - to children, 239
 - discussing bad news and, 51–53
 - of economic incentives of managed care systems, 202
 - of genetic testing results, 278–280
 - of gifts from drug companies, 212
 - informed consent and, 19–20
 - standards for, 22
 - surgery and, 244–247
 - of mistakes, 213–219, 296
 - case study of, 296
 - other health care professionals and, 218–219
 - to patient/surrogate
 - ethical response and, 216
 - reasons against, 213–215
 - reasons for, 214–215, 215t
 - situations not warranting, 216–218, 216–218
 - by trainees to attending physician, 217–218
 - patient need for information and, 47
 - to schools, 240
 - of secret, to patient, 174–175
 - surgery and, 244–247
 - alternative approaches and, 245
 - changes due to unanticipated findings and, 245–247
 - experience of surgeon and, 245
 - provider-specific outcomes and, 245
 - Discrimination
 - genetic, 276–277
 - by employers, 276–277
 - by insurers, 276–277
 - laws against, 277
 - Discussions
 - about advance directives, 83–86
 - bad news and, 51–53
 - about decision-making capacity, 72–73
 - about difficult doctor–patient relationships, 159–162
 - about DNR orders, 119–121, 120t
 - about family requests to withhold diagnosis from patient, 48–49

Discussions (*contd.*)

- about futile interventions, 64
- about health care rationing, 194
- about informed consent, 19–20, 25
- with Jehovah's Witnesses, 77
- about requests for life-sustaining interventions, 96
- with surrogates of patients, 93–94
- about uncovered/experimental treatment options, managed care restrictions on (gag rules), 201–203
- Diversion programs, for impaired colleagues, 223–224
- DNR/DNAR orders. *See* Do Not Resuscitate (DNR)/Do Not Attempt Resuscitation (DNAR) orders
- "Do no harm," principle of, 28–29
- Do Not Resuscitate (DNR)/Do Not Attempt Resuscitation (DNAR) orders, 117–123
 - discussing with patients, 119–121, 120r
- Emergency Medical Services and, 122
- implementing, 121–123
- implications of for other treatments, 121
- interpretation of, 121–122
- justifications for, 118–119
- "limited" or "partial," 121
- nursing home residents and, 122
- preventing misunderstandings regarding, 121
- slow or show codes and, 121–122
- writing, 121
- Doctor–patient relationship, 155
 - abuse of, sexual relationships with patients and, 170, 171
 - clinical research and, 176–181
 - context of, 157–158
 - difficult, 159–162
 - improving, 160–61, 160r
 - emergency care provision and, 161–162, 161
 - ethical obligations to care for patients and, 157–158
 - fiduciary nature of, 29–30
 - gifts from patients and, 163–167. *See also* Gifts
 - legal definition of, 158
 - managed care organizations affecting, 201–203
 - occupational risks to physician and, 158–159
 - HIV infection and, 158
 - responding to, 159
 - overview of, 155
 - refusal of care and, 157–161
 - sexual contact and, 168–173. *See also* Sexual contact
 - between physicians and patients
 - terminating, 161
 - with child, 239–241
 - with parents of patient, 239–241
- Domestic violence, reporting, 43
- Donation, organ, for transplantation. *See* Organ donation
- Donor cards, 265–269, 265–269
- Double effect doctrine, 107–108
- legal rulings and, 150
- Drinking/liquids, patients refusing, 109, 125–128. *See also* Intravenous feedings; Tube feedings
- Drivers, potential impairment of, reporting to public officials, 40
- Drug manufacturers
 - gifts from, 209–212
 - continuing medical education/conferences as, 209–210
 - objections to accepting, 210–211, 210r
 - objectivity affected by, 210–211
 - reasons for accepting, 210–211
 - reasons for offering, 209–210
 - reciprocity and, 210
 - recommended solutions and, 211–212
 - small, 209
 - types of, 209–210
 - research funded by, 180

- Durable power of attorney for health care (health care proxy), 80–82. *See also* Surrogate
- Duty, 14. *See also* Guidelines

E

- Eating/food, patients refusing, 109, 125–128. *See also* Intravenous feedings; Tube feedings
- Elder abuse, reporting, 42–43
- Electroencephalogram, in brain death determination, 144
- Emancipated minors, 238–241
- Embryos, frozen, 251
- Emergencies
 - implied consent and, 23, 73
 - obstetrical, 252
 - parental permission and, 238
 - questionable decision-making capacity and, 73
- Emergency care, obligation to provide, 161–162, 161
- Emergency departments, DNR orders and, 122
- Emotional reactions
 - to physician-assisted suicide, 135
 - to withdrawing/withholding life-sustaining interventions, 109–110
- Emotional stress, surrogate decision making affected by, 92
- Emotional support, ethics case consultation and, 112
- Ethical dilemmas in patient care, 3–9. *See also* Clinical ethics; Decision making, ethical; Ethical issues
 - approach to in clinical medicine, 6–9, 7r
 - clinical ethics and, 3–6
 - use of by physicians, 5–7
 - clinical research and, 176–181
 - ethics committees and, 8, 111–116
 - resolving, 8–9. *See also* Case consultations
 - case consultation in, 111–116
 - guidelines for, 10
 - students and house staff and, 226–231
- Ethical issues
 - areas of consensus and controversy about, 6
 - clarification of, 7–8
 - case consultation in, 111–113
 - identification of, 6
 - in obstetrics and gynecology, 250–255
 - in organ transplantation, 265–272
 - in pediatrics, 235–242. *See also* Children
 - in psychiatry, 257–263
 - in surgery, 244–249
- Ethics
 - caring, 15
 - casuistry and, 14–15
 - clinical, 3–6. *See also* Clinical ethics; Decision making, ethical
 - guidelines for, 10
 - conflicting, 13
 - exceptions to, 12–13
 - interpretation of, 12–13
 - use of, 12
 - morality differentiated from, 4–5
 - theories of, 13
 - virtue, 15
- Ethics committees, 114–115
 - for case consultation, 8, 111–116. *See also* Case consultations
 - advantages of, 115
 - disadvantages of, 115
 - interdisciplinary membership of, 115
- Ethics consultants, 8
 - bias, 113
 - for case consultation, 8, 111–116. *See also* Case consultations
 - disadvantages of, 115
 - document recommendations, 114

Ethics cons
individu
primary
Ethnic bac
insistenc
transplai
Euthanasia
active. S
passive,
Extended c
Extraordin

F

Family pla
Family/sigr
active et
concerns
disclosu
case s
ethica
other
reason
reason
situat
disclosu
discussio
discussio
meeting
as surrog
legal
Federal He
Feeding pr
Feeding tut
Fee-for-ser
conflicts
increase
problem
Fetus
as patien
mater
preventio
comp
routin
Fiduciary re
conflicts
definition
Financial in
balanced
bedside
conflicts
decreasin
increasin
for organ
research
Finder's fee
Food
as gift fr
patients
Formulary
Friends. *See*
Frozen emb
Futile inter
best inte
cardiopu
definition
loose,
strict,

Subject Index

Ethics consultants (*contd.*)
 individual bias affecting, 115
 primary data gathering by, 112, 115
 Ethnic background
 insistence on life-sustaining interventions and, 98
 transplant recipient selection and, 271
 Euthanasia
 active. *See* Active euthanasia
 passive, 131
 Extended care facilities, DNR orders for residents of, 122
 Extraordinary care, 106. *See also* Life-sustaining interventions

F

Family planning, providing information about, 251–252
 Family/significant others
 active euthanasia requests by, 137
 concerns of about disclosure, 48
 disclosure of mistakes to
 case study of, 296
 ethical response and, 216
 other health care workers and, 218–219
 reasons against, 213–215
 reasons for, 214–15, 215r
 situations not warranting, 216–218, 216–218
 disclosure of patient information to, 38–39
 discussion of DNR orders with, 119–121, 120r
 discussion of futile interventions with, 65
 meeting with, decision making and, 8
 as surrogate, 91–92. *See also* Surrogate
 legal issues regarding, 92
 Federal Health Privacy Regulations on confidentiality, 37
 Feeding problems, tube and intravenous feedings for, 125.
See also Intravenous feedings; Tube feedings
 Feeding tube. *See* Tube feedings
 Fee-for-service reimbursement
 conflicts of interest and, 187
 increases in services and, 196
 problems with, 196
 Fetus
 as patient, 251
 maternal/fetal conflict and, 253–254
 prevention of harm to, 251, 253–254
 compelled treatment of pregnant woman and, 77–78
 routine prenatal testing and, 252
 Fiduciary relationship, between doctor and patient, 29–30.
See also Best interests of patient
 conflicts of interest and, 187
 definition of, 29–30
 Financial incentives
 balanced, 202, 205
 bedside rationing of health care and, 192–193
 conflicts of interest and, 187
 decreasing services and, 187, 201–202, 205
 increasing services and, 187, 196–198
 for organ donation, 267–270
 research ethics and, 180
 Finder's fees, for research subject, 179
 Food
 as gift from drug company, 209
 patients refusing, 109, 125–128. *See also* Intravenous
 feedings; Tube feedings
 Formulary restrictions, bedside rationing and, 193
 Friends. *See* Family/significant others
 Frozen embryos, 251
 Futile interventions, 61–65
 best interests differentiated from, 64
 cardiopulmonary resuscitation as, 118–119
 definition of
 loose, 62–63
 strict, 61–63, 62r

discussion of, 64–65
 guidelines for, 65
 mistakes in judgments of, 63–65
 “no medical indications” and, 65
 problems with concept of, 63–65
 refusal to operate and, 246
 safeguards and, 64–65, 64r

G

Gag rules, in managed care, 201–203
 Gamete donation, 251
 Gatekeeper, physician as, 200, 205
 Genetic counseling, nondirective, 277–278
 Genetic testing, DNA-based, for predisposition to adult-onset
 disease, 274–280
 appropriate instances for, 274–277
 confidentiality and, 278–280
 discrimination and, 276–277
 informed consent and, 277–278
 nondirective counseling and, 277–278
 prenatal testing and carrier screening differentiated
 from, 274
 recommendations for, 278
 Gifts
 from drug companies, 209–212
 continuing medical education/conferences as, 209–210
 objections to acceptance of, 210–211, 210r
 objectivity affected by, 210–211
 reasons accepted, 210–211
 reasons offered, 209–210
 reciprocity and, 210
 recommended solutions and, 211–212
 small, 209
 types of, 209–210
 from patients, 163–167
 clinical judgment affected by, 165
 cultural significance for patient and, 164
 declining, 166
 doctor-patient relationship affected by, 164–165
 erosion of public trust and, 165
 as expression of appreciation, 163
 problems with, 164–165
 psychological needs of patient and, 163
 reasons for giving, 163–164
 responding to, 165–167
 sharing, 166
 soliciting, 165
 special treatment/unethical requests and, 164, 167

Goals

futility of care, 63
 patient, decisions consistent with, 69–70
 Gonorrhea
 prenatal testing for, 252
 public health reporting of, 40
 Guardian, court-appointed, as surrogate, 90–91
 Guidelines
 ethical, 10
 conflicting, 13
 exceptions to, 12–13
 interpretation of, 12
 use of, 12
 practice, in cost containment, 206
 Gynecology. *See* Obstetrics and gynecology

H

Handicapped infants, 242
 Harm
 bedside rationing of health care and, 190–192

- Harm (contd.)**
 disclosure of mistakes and, 214–217
 physician-patient sexual relationship and, 168
 preventing
 deception and nondisclosure in, 46
 “do no harm” principle and, 28–29
 impaired colleagues and, 221–222, 224
 treating patients against their wishes and, 77–78
- Health care costs**
 bedside rationing and, 189–194
 gifts from drug companies affecting, 210–211
 managed care systems’ decreases in services and, 200–206
 resource allocation and, 12, 33, 65, 189
 transplantation costs and, 271–272
- Health care institution/organization**
 mission of, insistence on life-sustaining
 interventions and, 99
 responsibility of for incentives to decrease services, 201–203
- Health care proxy/durable power of attorney for health care,**
 80–82. *See also* Surrogate
- Health Care Quality Improvement Act, 223–224**
- Health care resources. *See also* Health care services**
 allocation of, 12, 189
 cost of transplantation and, 271–272
 futility of interventions and, 65
 patient insistence on interventions and, 33
 bedside rationing of, 189–194
 arguments against, 190
 arguments supporting, 190–192, 190t
 financial resources as basis for, 192–193
 notification of patient/surrogate and, 194
 suggestions for physicians considering, 193–194, 194t
- Health care services. *See also* Health care resources**
 direct limitations on, in cost containment, 206
 incentives to decrease, 200–206
 cost-containment measures in managed care
 and, 205–206
 ethical concerns about, 201–202
 financial incentives and, 187, 201–202, 205
 patient requests for interventions and, 204–205
 responses of physicians to, 202–205
 responsibility of health care organizations and, 201–203
 incentives to increase, 196–198
 fee-for-service reimbursement, 196
 nonfinancial, 198
 self-referral, 196–198
- Health care team, in decision making, 8**
- Health care workers**
 beliefs about withdrawing life-sustaining
 interventions and, 99
 risk of acquiring HIV infection and, 158
- Health maintenance organizations (HMOs), 205.**
See also Managed care systems
- Heroic care, 106**
- Higher brain death, 144. *See also* Brain death**
 versus whole brain death, 144
- Hippocratic Oath**
 clinical ethics and, 5
 confidentiality addressed in, 36
- HIV infection/AIDS**
 partner notification and, 39, 41
 public health reporting of, 40
 transmission of in health care settings
 from patients to health care workers, 158
- HMOs. *See* Health maintenance organizations; Managed care
 systems**
- Hospital, mission of, insistence on life-sustaining
 interventions and, 100**
- Hospital ethics committees. *See* Ethics committees**
- Hospitalization, involuntary. *See* Involuntary
 psychiatric commitment**
- House staff**
 ethical dilemmas facing, 226–231
 learning on patients and, 226–228, 295
 case study of, 295
 in gynecological and obstetrical care, 254–255
 suggestions for, 230–231
 taking too much clinical responsibility and, 228–229
 unethical behavior/substandard care by other physicians
 and, 230–231, 295–297
 case study of, 295–297
 mistakes by, disclosure of, 217–219
- Human Genome Project, 274**
- Human immunodeficiency virus infection. *See* HIV
 infection/AIDS**
- Hunger. *See also* Intravenous feedings; Tube feedings**
 in patients refusing oral intake, 126

I

- Impaired colleagues, 221–225**
 causes of impairment/incompetence, 221
 concerns about intervening with, 222–223
 dealing with, 224–225, 224t
 legal issues regarding, 223–224
 protecting patient from, 221–222, 224
 reasons for intervening with, 221–223, 222t
- Impaired drivers, reporting to public officials, 40–41**
- Implied consent, 23**
- Incompetence. *See* Decision-making capacity, patient lacking**
- Incompetent physician, 223. *See also* Impaired colleagues**
- Individual consultants, 115**
- Infants, handicapped, 242**
- Infectious diseases**
 contact tracing/partner notification and, 41–42
 public health reporting of, 40
 treating against patient’s wishes, 77
 warning persons at risk and, 41–42
- Infertility treatment, 254**
- Information**
 comprehension of, decision-making capacity and, 71
 patient need for
 disclosure and, 47
 informed consent and, 19–20, 25
 provision of to third party
 deception and, 49–51
 overriding confidentiality and, 37t, 39–42, 40t
- Informed consent, 10, 17–26, 287**
 agreement with physician and, 17–18, 20
 assent of children, 235–236
 choices among alternatives and, 18
 surgery and, 245
 for clinical research, 177–179, 178t
 definition of, 17–18
 disclosure of experience of surgeon, 245
 disclosure of role of trainees, 254
 emergencies and, 23, 252
 exceptions to, 23–24
 for genetic testing, 277–278
 information discussed with patient and, 19–20, 25
 for invasive procedures by trainees, 227–230
 legal aspects of, 22–23
 as legal requirement, 18–19
 objections to, 20–22
 in obstetrics and gynecology, 251–252
 patient lacking decision-making capacity and, 20, 23
 patient refusal of interventions and, 19–20, 76
 patient self-determination and, 20
 patient well-being and, 18

Informed
 reasons
 require
 shared
 for surg
 therape
 waiver
 Insistence
 best in
 life-sus
 care;
 patie
 manage
 Institution
 Insurers
 decepti
 genetic
 Interventi
 Baby E
 best int
 child
 patie
 patie
 shan
 caregiv
 childre
 futile, t
 card
 handica
 incenti
 incenti
 inform
 agre
 choc
 st
 info
 mak
 patie
 patie
 patie
 shar
 unw
 manage
 parents
 patient
 patient
 best
 child
 by c
 deci
 info
 life-
 p
 shared
 appr
 best
 info
 unilate
 card
 child
 justi
 prot
 safe
 Intraveno

- Informed consent (*contd.*)
 reasons for, 18–19
 requirements for, 19–20
 shared decision-making and, 18–19, 18, 24–26, 24t
 for surgery, 244–247
 therapeutic privilege and, 23
 waiver of right of, 23–24
- Insistence on treatment
 best interests of patient and, 31–33. *See also* Futile interventions
 life-sustaining interventions and. *See also* Life-sustaining interventions
 caregiver insistence and, 99–101
 patient insistence, 95–99
 managed care and, 204–205
- Institutional Review Board, for clinical research, 179
- Insurers
 deception of, 49–51
 genetic discrimination by, 276–277
- Interventions (treatment). *See also* Care; Health care resources; Health care services
 Baby Doe Regulations and, 242
 best interests of patient and
 children and, 235, 237, 241–242
 patient insistence on, 31–34, 95–99
 patient refusal of, 11, 28–31
 shared decision making and, 24t, 24–26, 34t
 caregiver insistence on, 99–101
 children's preferences and, 235, 237, 241–242
 futile, 61–65
 cardiopulmonary resuscitation as, 118–119
 handicapped infants and, 242
 incentives to decrease, 200–206
 incentives to increase, 196–198
 informed consent regarding
 agreement and, 17–18, 20
 choosing among alternatives and, 18
 surgery and, 245
 information discussed with patients and, 19–20, 25
 making recommendations and, 25
 patient lack of decision-making capacity and, 20, 23
 patient lack of understanding of information and, 21
 patient refusal of treatment and, 19–20, 76
 patient unwillingness to make decision and, 21
 shared decision making and, 18–19, 24–26, 24t
 unwise/harmful choices and, 21, 26
 managed care and, 204–205
 parents' refusal of, 241–242
 patient insistence on, 31–34, 95–99
 patient refusal of
 best interests of patient and, 28–31
 children and, 241–242
 by competent/informed patients, 75–78
 decision-making capacity and, 67
 informed consent and, 19–20, 76
 life-sustaining interventions and, caregiver insistence and, 99–101
 patient transfer and, 100–101
 shared decision making about
 approach to, 59–60
 best interests of patient and, 24, 24t, 34t
 informed consent and, 18–19, 24–26, 24t
 unilateral decisions
 cardiopulmonary resuscitation and, 118–119
 children and, 237–239
 justification of, 61–63
 problems with, 63–65
 safeguards and, 64–65, 64t
- Intravenous feedings, 125–128
- burdens/benefits of, 127
 clinical recommendations regarding, 128–129
 legal status of, 128
 as life-sustaining intervention, 126
 as ordinary care, ethical distinctions regarding, 106
 prolonging dying and, 126
 prolonging life and, 126
 reasons for providing, 125–126
 as symbol of care, 127
 withdrawing
 versus withholding, 126
 withholding
 abuses and, 126
 hunger and thirst symptoms and, 126
 legal issues and, 128
 reasons for, 126–128
 starvation and, 126
- Invasive procedures
 suspension of DNR order for, 122
 trainees performing, 227–228
- Involuntary euthanasia, 130
- Involuntary psychiatric commitment, 258–260
 abuses and, 258
 decision-making capacity and, 72, 258
 procedures for, 258–260
 rationale for, 258
 refusal of treatment and, 262–263
 standards for, 258
 for suicidal patient, mitigating adverse consequences of, 260
- IRB. *See* Institutional Review Board
- J**
- Jehovah's Witnesses
 children and, 241
 increasing risk of surgery and, 247–249, 247
 refusal of blood transfusions by, 76–77
- Judgment
 conflicts of interest affecting, 186
 gifts from patient and, 165
 substituted. *See* Substituted judgment
- Justice
 allocation of health care resources and, 12
 transplant recipient selection and, 270–271
 conflicts and, 271
- L**
- Law. *See also* under Legal rulings
 clinical ethics and, 5–6
- Legal issues/status. *See also* Law
 active euthanasia and, 133–134, 135
 brain death and, 145
 clinical ethics and, 5–6
 competence standards and, 68–69
 family/significant other as surrogate and, 92
 impaired colleagues and, 223–224
 informed consent and, 18–19, 22–23
 life-sustaining interventions and, 147–151
 oral advanced directives and, 79–80
 tube and intravenous feedings and, 128
- Legal rulings. *See also* Law
 Abortion cases, 252–253
 Cruzan case, 148–149
 on life-sustaining interventions, 147–151
 Moore case, 180
 Physician-assisted suicide cases, 149–150
 Quinlan case, 147–148
 Schiavo case, 150–151
 Tarasoff case, 261

Life-sustaining interventions, 59–60. *See also*

Advance directives

Baby Doe Regulations and, 242

cardiopulmonary resuscitation as, withholding, 117–123

confusing ethical distinctions regarding, 105–110

distinction between withholding and withdrawing and, 105–106

handicapped infants and, 242

insistence on

caregiver (physician/hospital), 99–101

arguments for, 99

objections to, 97*t*, 99–101

timely and clear notification of patients and, 100

transferring patient and, 100–101

patient/surrogate, 95–99

clinical considerations and, 95–96

ethical considerations and, 96–97

patient suffering and, 97

recommendations for response to, 97–99, 100*t*

religious-based, 96–97

requests that “everything” be done and, 96

intravenous feedings as, 126. *See also* Intravenous feedings

legal issues and

legal rulings, 147–151

parents refusal of, 241–242

right of refusal, 100

tube feedings as, 126. *See also* Tube feedings

withdrawal of, negative vs. positive rights and, 100

withholding/withdrawing

assisted suicide/active euthanasia differentiated

from, 131

cardiopulmonary resuscitation and, 117–123

differentiating between withholding and withdrawing and, 105–106

discussing with physician, 82–86

emotional reactions to, 109–110

health care proxy and, 80–82

legal rulings on, 147–151

living wills regarding, 81

negative vs. positive rights and, 100

terminal sedation and, 108–109

Live donors, 268

Liver transplantation, for alcoholics, 271

Living wills, 81

Locked-in syndrome, persistent vegetative state differentiated from, 141

Lying, 45–46

definition of, 45

ethical objections of, 46

M

Macroallocation. *See* Health care resources, allocation of

Malpractice, informed consent and, 22

Managed care systems

compromises in quality of care and, 201

cost-containment measures in, 205–206

financial reimbursement in, conflicts of interest and, 187, 201–202, 205

incentives to decrease services and, 200–206

physician as gatekeeper in, 205

physician as patient advocate in, 203–205

Manipulation, informed consent and, 20

Maternal/fetal conflict, 253–254

Mature minors, 238

Meals, as gift from drug company, 209

Mechanical ventilation, withdrawal of, 105

emotional responses to, 109

legal rulings on

Quinlan case, 147–148

Schiavo case, 150–151

Medical interventions. *See* Interventions (treatment)

Medical paternalism, 31

Medical records

advance directive discussions documented in, 85

confidentiality of, 36–43. *See also* Confidentiality

DNR orders written in, 121

omitting sensitive information from, 38–40

Mental illness. *See* Psychiatric patient

Mental status testing, decision-making capacity assessment and, 70–72

Mercy killing, 130. *See also* Active euthanasia

Microallocation. *See* Health care resources, bedside rationing of

Minimally acceptable standard of conduct, legal vs. ethical actions and, 5

Minors

consent for treatment by, 238–241

emancipated, 238–241

mature, 238

parental consent for abortion and, 252–253

Misrepresentation. *See also* Deception; Nondisclosure

definition of, 45

resolving dilemmas about, 48–49, 48*t*

Mistakes, disclosure of, 213–219, 296

case study of, 296

other health care workers and, 218–219

to patient/surrogate

ethical response and, 218

reasons against, 213–215

reasons for, 214–215, 215*t*

situations not warranting, 216–218

by trainees to attending physician, 217–219

Moral exhortation, physician response to occupational risks and, 159

Moral guidance, clinical ethics as source of, 4

Moral values, personal, dilemmas in clinical ethics and, 3–5

Morality, ethics differentiated from, 4–5

N

Negative rights, 100

Neglect, child

Baby Doe Regulations and, 242

reporting, 42

Negligence, informed consent and, 22

No CPR order, 117. *See also* Do Not Resuscitate (DNR)/Do Not Attempt Resuscitation (DNAR) orders

Nondisclosure, 46–50. *See also* Deception; Disclosure

avoidance of, 11, 45–53

discussing bad news and, 51–53

definition of, 45

resolving dilemmas about, 48–49, 48*t*

Nonmaleficence, 11, 28

Nonvoluntary euthanasia, 130

“Not medically indicated,” futility and, 65

Nurses/nursing staff, beliefs about withdrawing life-sustaining interventions and, 99

Nutrition. *See* Feeding problems; Intravenous feedings; Tube feedings

O

Obstetrics and gynecology, ethical issues in, 250–255

abortion and, 252–253

providing information and, 251–252

adolescent patients and, 251–252

alcohol use during pregnancy and, 254

assisted reproductive technologies and, 251, 254

compelled treatment and, 77–78

Obstetrics &
family p
forced c
informe
life-sust

mother a
mater
obstetric
philosoph
prenatal
routin
sterilizat
student/t
substanc
third par

Occupation
HIV infe
reducing
respondi

Operating r
Opioids, hi
emotiona

Oral directi
legal stat
limitatio
statemen
statemen
trustwort

Oral intake.

Ordinary ca
tube and

Organ dona
criteria fi
current s
definition
donor ca
ethical c
financial
harvestin

live don
mandate
presume
proposak
required
routine n

Organ Proc
Organ trans
cost of. i
organ do
defini

recipient

repeat, a

P

Pain relief
high dos
emoti
for patie
Paramedic
Parental de
disagree
Partner abu
Partner noti

- Obstetrics and gynecology, ethical issues in (*contd.*)
 family planning information and, 251–252
 forced cesarean section deliveries and, 254–255
 informed consent in, 251–252
 life-sustaining interventions for brain dead mother until
 delivery and, 144
 mother and fetus as patients and, 251
 maternal/fetal conflict and, 253–254
 obstetrical emergencies and, 252
 philosophical/religious questions and, 250
 prenatal testing and
 routine, 252
 sterilization and, 252–253
 student/trainee participation in, 254–255
 substance abuse during pregnancy and, 254
 third party influences and, 250
 Occupational risks for health care workers, 158–159
 HIV infection and, 158
 reducing, 159
 responding to, 159
 Operating room. *See* Surgery
 Opioids, high doses of for symptom relief, 106–108
 emotional responses and, 109
 Oral directives (advanced), 79–81
 legal status of, 79–80
 limitations of, 79–80
 statements to family/friends, 79–81
 statements to physicians, 80–81
 trustworthiness of, 79–81
 Oral intake, patients refusing, 109, 125–128. *See also*
 Intravenous feedings; Tube feedings
 Ordinary care, 106
 tube and intravenous feedings as, ethical distinctions
 regarding, 106
 Organ donation, 265–270
 criteria for acceptable cadaver donors and, 265–270
 current system for, 265–269
 definition/determination of death and, 143, 145, 267–269
 donor card choices and, 267
 ethical concerns about, 265
 financial incentives for, 267–270
 harvesting organs from non-heart-beating cadaver donors
 and, 267–269
 live donors and, 268
 mandated choice and, 267
 presumed consent and, 267
 proposals to increase, 267–268
 required request laws and, 265
 routine notification laws and, 265
 Organ Procurement Organizations, 267
 Organ transplantation, 265–272
 cost of, 271–272
 organ donation and, 265–270. *See also* Organ donation
 definition/determination of death and, 143, 145,
 267–269
 recipient selection and, 269–272. *See also* Transplant
 recipient
 repeat, after rejection, 270

P

- Pain relief
 high doses of opioids/sedatives for, 106–108
 emotional responses and, 109
 for patients refusing tube and intravenous feeding, 127
 Paramedics, DNR orders and, 122
 Parental decision making, 237–238
 disagreements with pediatrician and, 237–239
 Partner abuse, reporting, 42–43
 Partner notification

- by physicians, 42
 by public health officials, 41
 Passive euthanasia, 131
 Paternalism, medical, 31
 Patient
 advance directives of, 59, 79–86
 surrogate selection and, 84, 91
 best interests of. *See* Best interests of patient
 cardiopulmonary resuscitation refused by, 118
 deceiving, avoidance of, 11, 45–53
 disclosure of mistakes to
 case study of, 296
 ethical response and, 218
 other health care workers and, 218–219
 reasons against, 214
 reasons for, 214–215, 215t
 situations not warranting, 216–218
 discussion about decision-making capacity with, 72–73.
See also Decision-making capacity
 discussion of bad news with, 51–53
 discussion of DNR orders with, 119–121
 discussion of futile interventions with, 64–65
 discussion of health care rationing with, 194
 discussion of information with, informed consent
 and, 19–20, 25
 gift-giving to physician by, 163–67. *See also* Gifts
 identification of trainee to, 226–228
 incompetent. *See* Decision-making capacity, patient lacking
 learning procedures on, 226–228, 295
 case study of, 295
 in gynecological and obstetrical care, 254–255
 in managed care system, physician as advocate
 for, 203–205
 preferences/values of, surrogate decisions
 inconsistent with, 92
 refusal to care for, 157–161, 287–297
 case study of, 287–297
 doctor–patient relationship and, 157–158
 difficult, 159–162, 160r
 obligations to provide emergency care and, 161
 occupational risks to physicians and, 158–159
 surgery and, 246–247
 relationship of with physician. *See* Doctor–
 patient relationship
 respect for, 10–11
 confidentiality and, 36
 sexual contact with physician and, 168–173. *See also*
 Sexual contact between physicians and patients
 surrogate selection by, 84, 91
 unwillingness of to know diagnosis, deception/
 nondisclosure and, 47
 Patient abandonment, 161
 Patient advocate
 for children, pediatrician as, 235–237
 physician in managed care system as, 203–205
 Patient autonomy. *See* Autonomy
 Patient care, ethical dilemmas in, 3–9. *See also* Decision-
 making, ethical
 Patient confidentiality. *See* Confidentiality
 Patient self-determination, respect for, informed consent and, 20
 Patient transfer
 refusal of life-sustaining interventions and, 100–101
 Patient well-being, enhancing, informed consent and, 18–19
 Pediatrics, ethical issues in, 235–242. *See also* Children
 Pelvic examination, by student/trainee, on patient under
 anesthesia, 228, 255
 Persistent vegetative state, 140–142
 appropriate treatment in, 141–142

- Persistent vegetative state (*contd.*)
 clinical features of, 140–141
 definition of, 141
 tube feedings and, 141–142
 withholding/withdrawing interventions and, 141–142
 Cruzan case ruling and, 148–149
 Quinlan case ruling and, 147–148
 Schiavo case ruling and, 150–151
- Physician
 attending, disclosure of trainee mistakes to, 217–219
 as gatekeeper, 200, 205
 impaired, 221–225. *See also* Impaired colleagues
 as patient advocate
 for children, 235–237
 in managed care system, 203–205
 sexual contact with patient and, 168–173. *See also* Sexual
 contact between physicians and patients
 solicitation of gifts from patients by, 165. *See also* Gifts
- Physician-assisted suicide, 130–138, 287–295
 abuse and, 131
 actual use of prescribed drugs and, 135
 administering appropriate doses of narcotics/sedatives
 differentiated from, 131
 case study of, 287–295
 compassion for suffering patient and, 132
 de facto legalization of in Netherlands, 135
 declining request for, 137
 definition of, 130
 physician confusion about, 134
 depression and, 134
 emotional impact of on physician, 135
 improved palliative care affecting patient desire for, 136
 incidence of requests for, 134
 justifiable situations and, 137
 legal rulings on, 149–150
 legalization of in Oregon, 133–134
 manageability of suffering and, 132
 patient withdrawal of request for, 135
 physician role as healer and, 133
 policy options and, 135–136
 reasons favoring, 131–132
 response to request for, 136–138
 safeguard violations and, 135
 sanctity of life and, 132
 withholding/withdrawing medical interventions
 differentiated from, 131
- Physician autonomy
 patient insistence on interventions and, 32
 physician/caregiver insistence on life-sustaining interventions
 and, 99
- Physician–patient relationship. *See* Doctor–patient relationship
- Positive rights, 100
- Power of attorney for health care, durable (health care proxy),
 80–82. *See also* Surrogate
- PPOs. *See* Managed care systems; Preferred provider
 organizations
- Practice guidelines, in cost containment, 206
- Preferred provider organizations (PPOs), 205. *See also*
 Managed care systems
- Pregnancy. *See also* Obstetrics and gynecology
 compelled treatment and, 77–78
 ethical issues in, 250–255
 life-sustaining interventions for brain dead mother until
 delivery and, 144
 philosophical/religious questions about, 250
 substance and alcohol abuse during, 254
- Prenatal testing
 differentiation of from DNA-based testing for adult-onset
 diseases, 274
 routine, 252
- Preventing harm. *See* Harm, preventing
- Principles, 13–14. *See also* Guidelines
- Privacy, sexual relationship between patient and physician
 and, 168
- Product recognition, drug company gifts and, 210
- Professional oaths/codes, clinical ethics differentiated from, 5
- Professionalism. *See also* Doctor–patient relationship
 gifts from drug companies affecting, 210–211
 impaired colleagues and, 222
 nature of, best interests of patient and, 29–30
 nondisclosure of mistake affecting, 215
 physician-patient sexual relationship and, 170
 self-referral and, 196–198
 American Medical Association (AMA) standards
 and, 197
- Promise-keeping, 11, 54–56
 ethical significance of, 54–55
 guidelines for, 55–56
 problems with, 55
- Protection of victims, overriding confidentiality and, 42,
 261–263
- Protocols, in cost containment, 206
- Provider-specific outcomes, disclosure of, 245
- Proxy, for health care (durable power of attorney for health
 care), 80–82. *See also* Surrogate
- Psychiatric patient
 decision-making capacity and, 272, 257, 258
 refusal of psychiatric treatment and, 262–263
 ethical issues in care of, 257–263
 confidentiality and, 258
 danger to others and, 260–263
 impairment and, 257
 involuntary commitment and, 258–260
 mitigating adverse effects of, 260
 refusal of treatment and
 medical treatment, 263
 psychiatric treatment, 262–263
 risk of abuses and, 257–259
 suicide threats and, 258–260
 violence by, 260–263
 warning persons at risk and, 41, 261–263
- Psychiatrists, consultation by, decision-making
 capacity assessment and, 71–72
- Psychosocial issues, dealing with in ethical
 dilemmas, 8
- Public figures, release of information about, 38
- Public health officials
 partner notification by, 41
 reporting patient information to, 40–41
- PVS. *See* Persistent vegetative state
- Q**
- Quality of life
 assessment of, 30
 best interests of patient and, 30
 futility of interventions and, 63
 cardiopulmonary resuscitation and, 119
- Quinlan case, 147–148
- R**
- Randomization, in clinical research, 176–177
- Randomized controlled trials, 176–177
- Rationing health care. *See* Allocation of resources; Bedside
 rationing of health care
- Reality, distorted views of, decision-making capacity affected
 by, 70
- Reasoning, use of, decision-making capacity and, 70–71
- Reciprocity, gifts from drug company and, 210

Refractory
 high do
 emot
 Refusal of
 best int
 by com
 decisio
 inform
 by Jeh
 child
 incre
 of life-
 care
 patie
 by pare
 by psyc
 medi
 psyc
 respecti
 restrict
 scope o
 surgery
 Refusal to
 case st
 doctor-
 diffi
 obligati
 occupa
 surgery
 Reimburs
 as conf
 decreas
 increas
 Relatives.
 Religious
 insister
 unconv
 Reporting
 child al
 crimes
 domest
 drug/al
 elder al
 impair
 impair
 to publ
 unethical
 Reproduc
 Research
 compet
 confide
 conflic
 constr
 drug m
 finder
 informa
 Institut
 particip
 patient
 researc
 Research
 Resource
 allocat
 cost
 futil
 pati

- Refactory symptoms/suffering
 high doses of opioids/sedatives for symptom relief
 and, 106–108
 emotional responses and, 109
- Refusal of treatment
 best interests of patient and, 11, 28–31
 by competent/informed patients, 75–78
 decision-making capacity and, 67
 informed consent and, 19–20, 76
 by Jehovah's Witnesses, 76–77
 children and, 241
 increasing risk of surgery and, 247–249, 247
 of life-sustaining interventions. *See also* Advance
 directives; Life-sustaining interventions
 caregiver insistence and, 99–101
 patient transfer and, 100–101
 by parents for children, 241–242
 by psychiatric patients
 medical treatment, 263
 psychiatric treatment, 262–263
 respecting, 75
 restrictions on, 77–78
 scope of, 75–76
 surgery and, 247–249
- Refusal to care for patient, 157–161, 287–297
 case study of, 287–297
 doctor–patient relationship and, 157–158
 difficult, 159–162, 160t
 obligations to provide emergency care and, 161
 occupational risks to physicians and, 158–159
 surgery and, 246–247
- Reimbursement incentives. *See also* Financial incentives
 as conflicts of interest, 187
 decreases in services and, 201–202
 increases in services and, 196–198
- Relatives. *See* Family/significant others
- Religious beliefs
 insistence on life-sustaining interventions and, 96–97
 unconventional decisions based on, 72–73
- Reporting
 child abuse, 42–43
 crimes involving injuries, 41
 domestic violence, 43
 drug/alcohol use during pregnancy, 254
 elder abuse, 42–43
 impaired automobile driver, 40–41
 impaired colleagues, 223, 224–225
 to public health officials, 40–41
 unethical behavior/substandard care by senior
 physician, 230–31
- Reproductive technologies, assisted, 250–251, 254
- Research ethics, 176–181
 competing interests and, 179–181
 confidentiality of data from, 179
 conflicting interests and, 180
 constrained consent and, 177
 drug manufacturer funding and, 180
 finder's fees and, 179
 informed consent and, 177–179, 178t
 Institutional Review Board and, 179
 participant selection and, 177
 patient lacking decision-making capacity and, 177
 research protocols and, 176–179
- Research protocols, design of, 176–177
- Resources
 allocation of, 12, 189
 cost of transplantation and, 271–272
 futility of interventions and, 63
 patient insistence on interventions and, 33

- bedside rationing of, 189–194
 arguments against, 190
 arguments supporting, 190–192, 190t
 financial resources as basis for, 192–193
 notification of patient/surrogate and, 194
 suggestions for physicians considering, 193–194, 194t
- Respect for persons, 10–11
 confidentiality and, 36
- Retransplantation, 270
- Rh type, prenatal testing for, 252
- “Right to die.” *See* Active euthanasia; Life-sustaining
 interventions; Physician-assisted suicide
- Rights, claims of, as justification of action, 4
- Rubella, prenatal testing for, 252
- Rule, 14. *See also* Guidelines

S

- Safeguards
 assisted suicide/active euthanasia and, 134
 futile interventions/unilateral decision-making and,
 64–65, 64t
- Salary, as cost-containment measure, 205. *See also* Financial
 incentives
- Schiavo case, 150–151
- Schizophrenia, decision-making capacity and, 72
- Schools, disclosure of information to, 240
- Second opinion, futile interventions and, 64
- Secrets, physician's response to, 174–175
- Sedation, terminal, 108–109
- Sedatives, high doses of for symptom relief, 106–108
 emotional responses and, 109
- Self-determination, patient, informed consent and, 20
- Self-referral by physicians, 196
 justification, 196–198
- Sexual contact between physicians and patients, 168–173
 abuse of doctor–patient relationship and, 169–171
 justifications for, 168–169
 legal issues and, 170
 objections to
 current patients and, 169–171, 169t
 former patients and, 171–172
 prevalence of, 168
 responding to advances by patients and, 172
 suggestions for physicians considering, 172–173
- Sexually transmitted diseases, partner notification and, 41
- Shortness of breath, high doses of opioids/sedatives for relief
 of in terminal patients, 107
- Show code, 121–122
- Significant others. *See* Family/significant others
- Slippery slope argument
 physician-assisted suicide/active euthanasia and, 133
 withholding tube and intravenous feedings
 and, 126, 128
- Slow code, 121–122
- Spousal abuse. *See* Domestic violence
- Standard of conduct, minimally acceptable, legal vs. ethical
 actions and, 5
- Standards for disclosure, informed consent and, 22
- Starvation, withholding tube and intravenous feedings
 and, 126
- Sterilization, informed consent and, 252–253
- Students
 ethical dilemmas facing, 226–231
 introducing students to patients, 226–227
 learning on patients and, 226–228, 295
 case study of, 295
 in gynecological and obstetrical care, 254–255
 suggestions for, 230–231

Students (*contd.*)

- taking too much clinical responsibility and, 228–229
- unethical behavior/substandard care by other physicians and, 230–231, 295–297
 - case study of, 295–297
- mistakes by, disclosure of, 217–219
- Substance abuse, during pregnancy, 254
- Substituted judgment, 85–88
 - conflict with patient's best interests and, 87
 - inaccuracy of, 86
 - inconsistency of, 86
 - problems with, 86–88
- Suffering, requests for interventions causing, 97
- Suicidal patients, 259–260
 - identification of, 260
 - interventions for prevention and, 259–260
 - involuntary hospitalization of, mitigating adverse consequences of, 260
- Suicide, assisted. *See* Physician-assisted suicide
- Surgeon, disclosure of experience of, 245
- Surgery
 - ethical issues in, 244–249
 - disclosure of information and, 244–247
 - informed consent and, 244–247
 - patient requests that increase risk and, 247–249
 - refusal of surgery and, 247–249
 - refusal to operate and, 246–247
 - suspension of DNR order for, 122
- Surrogate, 59, 90–94. *See also* Family/significant others
 - active euthanasia requests by, 131, 134, 138
 - cardiopulmonary resuscitation refused by, 118
 - court-appointed guardian as, 90–91
 - decision making by, 90–94
 - conflicts of interest and, 92–93
 - disagreements among family members and, 93
 - discussing with patient, 85
 - emotional stress affecting, 92
 - improving, 93–94, 93t
 - inconsistency with patient preference/values and, 92
 - legal issues regarding, 92
 - problems with, 92–93
 - disclosure of mistakes to
 - case study of, 296
 - ethical response and, 218
 - other health care workers and, 218–219
 - reasons against, 213–215
 - reasons for, 214–215, 215t
 - situations not warranting, 216–218
 - discussion of DNR orders with, 119–121, 120t
 - discussion of futile interventions with, 64–65
 - discussion of health care rationing with, 194
 - family member as, 91–92
 - for patient with no family member available, 92
 - insistence on life-sustaining interventions by, 95–99
 - selection of, 90–92
 - by patient, 84, 91
- Surrogate motherhood, 251
- Syphilis, prenatal testing for, 252

T

- Tarasoff case, 261
- Teaching hospital, implied consent for trainee care and, 226–228. *See also* Trainees
- Terminal illness
 - refractory symptoms/suffering and
 - high doses of opioids/sedatives for relief of, 106–108
 - emotional responses and, 109
 - responses to, 108–109

voluntary stopping of eating and drinking and, 109, 125–128.

See also Intravenous feedings; Tube feedings

Terminal sedation, 108–109

Therapeutic privilege, 23

Third parties

deception of, 49–51

resolving dilemmas about, 50–53, 53t

influence of on reproductive health, 250

protection of

bedside rationing of health care and, 190–192

overriding confidentiality and, 37t, 39–42, 40t

treating patients against their wishes and, 77–78

Thirst. *See also* Intravenous feedings; Tube feedings

in patients refusing oral intake, 126

Tiered formulary benefits, bedside rationing and, 193

Trainees

ethical dilemmas facing, 226–231

learning on patients and, 226–228, 295

case study of, 295

in gynecological and obstetrical care, 254–255

suggestions for, 230–231

taking too much clinical responsibility and, 228–229

unethical behavior/substandard care by other physicians and, 230–231, 295–297

case study of, 295–297

mistakes by, disclosure of, 217–219

Transfusions (blood), refusal of by Jehovah's

Witnesses, 76–77

children and, 241

increasing risk of surgery and, 247–249, 247

Transplant recipient, selection of, 269–272

beneficence and, 269–270

conflicts between guidelines and, 271

historical background of, 269

justice and, 270–271

patient behaviors causing disease and, 271–272

Transplantation, 265–272

cost of, 271–272

organ donation and, 265–270. *See also* Organ donation

definition/determination of death and, 143, 145, 265

recipient selection and, 269–272. *See also* Transplant

recipient, selection of

repeat, after rejection, 270

Treatment. *See* Interventions

Truth-telling, 45. *See also* Deception; Misrepresentation

Tube feedings, 125–128

burdens/benefits of, 127

clinical recommendations regarding, 128–129

legal status of, 128

as life-sustaining intervention, 126

as ordinary care, ethical distinctions regarding, 106

persistent vegetative state and, 141–142

prolonging dying and, 126

prolonging life and, 126

reasons for providing, 125–126

reasons to provide, 125

as symbol of care, 127

withdrawing

Cruzan case ruling and, 148–149

withholding

abuses and, 126

hunger and thirst symptoms and, 126

legal issues and, 128

reasons for, 126–128

starvation and, 126

Tuberculosis

contact tracing/warning persons at risk and, 41

public health reporting of, 40

U

Uncon:
Unifor
Unilate
aboi
for c
justi
prob
safe
United
UNOS
Utilitar

V

Values.
Vegetat
defu
pers
aj
cl
ca
tu
w

99, 125-128.
things

12

Or

1-78

igs

193

1-255

1-229

r physicians

donation

145, 265

splant

nation

106

Subject Index

U

Unconscious patient, learning procedures on, 228, 255
Uniform Anatomical Gift Act, 265
Unilateral decision making
 about cardiopulmonary resuscitation, 118-119
 for children, 237-239
 justification of, 61-63
 problems with, 63-65
 safeguards and, 64-65, 64r
United Network for Organ Sharing (UNOS), 269
UNOS. *See* United Network for Organ Sharing (UNOS)
Utilitarian theories, of clinical ethics, 13

V

Values, patient, decisions consistent with, 69-70
Vegetative state
 definition of, 140
 persistent, 140-142
 appropriate treatment in, 141-142
 clinical features of, 140-141
 definition of, 141
 tube feedings and, 141-142
 withholding/withdrawing interventions and, 141
 Cruzan case ruling and, 148-149
 Quinlan case ruling and, 147-148
 Schlavo case ruling and, 150-151

Ventilation, mechanical, withdrawal of, 105
 emotional responses to, 109
 Quinlan case ruling on, 147-148
 Schlavo case ruling on, 150-151
Veracity, 45. *See also* Deception; Misrepresentation
Violence
 domestic, reporting, 43
 by psychiatric patient, 260-263
 warning persons at risk and, 41, 261-63
Virtue ethics, 15
Voluntary euthanasia, 130. *See also* Active euthanasia

W

Waivers of confidentiality, 37
Weapons, injuries caused by, reporting, 41
Well-being, patient, informed consent and, 18-19
Whistleblowing. *See* Reporting
Whole-brain death, 143-144. *See also* Brain death
 versus higher brain death, 143-144
Withholding information/diagnosis. *See* Deception;
 Nondisclosure
Withholding interventions. *See* Futile interventions; Life-
 sustaining interventions, withholding/withdrawing
Withholding payment, as cost-containment measure, 205. *See*
 also Financial incentives
Work absences, physician certification of, deception and, 49-50